



HIV

AUSTRALIA

HIV in regional, rural and remote Australia

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AFAO is the national federation for the HIV community response, providing leadership, coordination and support to the Australian policy, advocacy and health promotion response to HIV/AIDS. Internationally, AFAO contributes to the development of effective policy and programmatic responses to HIV/AIDS at the global level, particularly in the Asia Pacific region.

AFAO's aims are to:

- Advocate on behalf of its members at the federal level, thereby providing the HIV community with a national voice;
- Stop the transmission of HIV by educating the community about HIV/AIDS, especially those whose behaviour may place them at high risk;
- Assist its members to provide material, emotional and social support to people living with HIV;
- Develop and formulate policy on HIV issues;
- Collect and disseminate information for its members;
- Represent its members at national and international forums; and
- Promote medical, scientific and social research into HIV and its effects.

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This edition of *HIV Australia* examines key issues for people living with HIV in regional, rural and remote communities.

Contributors from around the country highlight a range of common themes including: stigma and isolation; fear of disclosure and the need to protect anonymity; a shortage of local health services, s100 providers and HIV-experienced GPs; ageing of the HIV-positive population; a reluctance to access local services and the need to travel long distances to receive confidential clinical care and medication.

Images in this edition are taken by photographers who live and work in regional and rural areas: Panos Couros, Care and Support Coordinator at NTAHC in the Northern Territory (front cover image and pages 7, 9, 15, 27, 31, 33 and 36); Tobin Saunders, Community Health Promotion Officer at ACON, Northern Rivers (pages 21, 24 and 29); and Jorge Henao, a photographer from Pottsville, NSW (pages 12 and 18).

This will be the final edition of *HIV Australia* for 2012. From next year, *HIV Australia* will be published three times per year. Contact editor@afao.org.au for comments, feedback and submission ideas.

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HIV Australia welcomes submissions from interested authors. To submit an article or report for consideration, email editor@afao.org.au



NEWS

AUSTRALIA

Rise in HIV diagnoses 'a call to action'

The number of new HIV diagnosis in Australia increased by 8% between 2010 and 2011, and by 50% in the past decade, according to new HIV surveillance figures released by the Kirby Institute on 17 October.

The *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2012* shows an increase in new HIV diagnoses from 1,051 in 2010 to 1,137 in 2011. Increases in Victoria, New South Wales, and South Australia were primarily among men who have sex with men.

Rob Lake, AFAO Executive Director, described the increase as 'a call to action'.

'We know the tools we need, but the political will and policy action must be there to change the number of HIV transmissions,' Mr Lake said.

AFAO has joined with other national HIV organisations and research bodies to produce the Melbourne Declaration, an action plan which identifies priority actions that are critical if Australia is to meet the targets outlined in the *United Nations 2011 Political Declaration on HIV/AIDS* (UNPD). The Melbourne Declaration calls for a strengthening of the partnership between community, government and research centres and professional organisations.

The UNPD targets, to be met by 2015, include reduction of annual domestic HIV infection rates by 50% and increasing the number of people with HIV on treatments, through expediting access to testing, treatment and pre-exposure prophylaxis (PrEP).

For further information, and to sign the Melbourne Declaration visit www.melbournedeclaration.com

Boost to health workforce in regional and remote areas

Mark Butler, Acting Minister for Health, has announced \$17.69 million worth of funding for two major projects aimed at boosting the healthcare workforce in rural areas.

The first project, the Rural Health Professionals Program, will facilitate the recruitment of 387 additional nursing and allied health workers, in Australia's first nationally coordinated recruitment drive for health workers. The second project will roll out eight nation-wide education initiatives enabling doctors to undertake advanced training relevant to the needs of rural communities, focusing on the roles of Rural Medical Generalists and rural 'dual trained' physicians. These initiatives aim to address issues relating to increasing use of 'fly-in, fly-out' services in remote and rural locations.

'Both projects are innovative examples of health workforce reform and address our key aims of building capacity, boosting productivity and improving distribution of rural health professionals,' Mr Butler said.

The announcement is particularly timely given the recent release of a University of Melbourne report, *Getting Doctors into the Bush: General Practitioners' Preferences for Rural Location*. The study, surveying nearly 4,000 GPs, found an urgent need for incentives to encourage more GPs to focus on servicing rural communities.

Chlamydia and gonorrhoea on the rise

Rates of chlamydia and gonorrhoea increased significantly in 2011, continuing a trend in recent years, according to the Kirby Institute's *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2012*, released 17 October.

Gonorrhoea has increased by 21% since 2010, with 12,807 diagnoses in 2011. Most cases are among men who have sex with men. Chlamydia remained the most frequently reported notifiable condition in Australia, with 80,800 cases diagnosed in 2011 compared to 74,305 cases in 2010. Most of these infections were in young heterosexual people.

Professor David Wilson of the Kirby Institute described the figures as 'just the tip of the iceberg'. Chlamydia is of particular concern because it can cause infertility in women and inflammation of the testicles and sperm conducting tubes in men; and for both men and women, as with all STIs, chlamydia can increase the transmissibility of, and susceptibility to, HIV.

Increased rates of infectious syphilis in 2011 occurred in Queensland, South Australia, Victoria and Western Australia, however there has been a drop in diagnoses of genital warts (following the introduction of a vaccination program) and hepatitis B diagnoses. Hepatitis C diagnoses remained stable.

STI rates surge among Aboriginal and Torres Strait Islanders

New figures show a significantly higher rate of sexually transmitted infections (STIs) among Aboriginal and Torres Strait Islanders compared to other Australians – particularly in rural areas and among young people.

Findings published by the Baker International Diabetes Institute in Alice Springs show that chlamydia rates are three times higher than among other Australians; syphilis rates are five times higher; and gonorrhoea rates are thirty times higher than among non-Indigenous Australians.

Speaking to SBS World News about the findings, Baker Institute researcher, James Ward, highlighted some of the challenges in addressing rates of STIs in rural communities: '... there are a whole range of issues when you are working in remote areas to get the treatment to people, especially when you've sent the test off to the lab and the result comes back five or seven days later ... you've got to find people again and they might have moved to a different community by then for business or for other reasons.'

At the 13th IUSTI World Congress held in Melbourne in October, which incorporated the Australasian Sexual Health Conference, Mr Ward made an impassioned plea for action: 'We've made improvements in other areas of health disparity for Aboriginal people, why can't we do it with STIs?'

New legal defence for non-disclosure of HIV in NSW

People with HIV in NSW who have been charged with a public health offence for failing to disclose their HIV status to sexual partners may now use taking 'reasonable precautions' as a defence.

Significantly, this amendment to the NSW legislation does not change the legal requirement that people with HIV disclose their status before sex. What is now permitted, under the amended public health law, is a legal defence of taking 'reasonable precautions' if a person is charged with an offence in relation to an alleged failure to disclose their HIV-positive status before sex. This defence is yet to be tested in court; however, HIV legal experts have indicated that proper condom use is likely to be considered as taking 'reasonable precautions'.

This new defence has no bearing on criminal charges for HIV transmission.

Queensland man charged with non-disclosure of HIV status prior to sex

A 20-year-old HIV-positive man in Queensland has been charged in relation to allegedly having unprotected sex with two men, in separate incidents, and knowingly failing to disclose his HIV status. The formal charge was recklessly putting someone else at risk of contracting a controlled notifiable condition.

The *Star Observer* reports that bail was initially refused on the grounds that the man was at risk of committing another offence. The magistrate ultimately

decided to grant bail given that the man had voluntarily turned himself into police and had accompanied the other men involved to undergo HIV testing. The prosecution did not oppose bail but are seeking the maximum sentence of 18 months.

Rapid HIV testing trial in Sydney

Point of care rapid HIV testing (RHT) is now available to gay and bisexual men attending four sexual health clinics in Sydney as part of a study designed to identify how best to integrate RHT into existing testing services. The study is also assessing the patient experience of RHT, as well as the experiences of staff who have been trained to deliver the tests.

The rapid tests are free of charge and by appointment only. Further information at: www.acon.org.au/hiv/rapid-HIV-testing

Victoria's health department has also recently announced that it will trial rapid HIV testing in the coming months.

Concerns over the Queensland Government's HIV response

The Queensland Government established a new Ministerial Advisory Committee on HIV/AIDS in July, following an announcement made by the Queensland Health Department in May that it was cutting funding to Queensland's peak HIV/AIDS body Healthy Communities (QAHC) for HIV prevention. Until 18 August, when the defunding decision took effect, Healthy Communities was funded by Queensland Health to deliver

HIV prevention services for gay and other men who have sex with men. The reallocation of this funding is to be determined by the newly formed Ministerial Advisory Committee.

Dr Wendell Rosevear announced his resignation from the new Committee in September, saying that he refuses to be used as a rubber stamp for a predetermined agenda. According to the gaynewsnetwork.com.au, Dr Rosevear stated in an open letter to Health Minister Lawrence Springborg that the Government's decision to cease funding QAHC for HIV prevention amounts to a breaking of trust with the community, and that the Government's unwillingness to reconsider the decision was unacceptable.

Concerns have also been raised about the Queensland Government's recent revival of the Grim Reaper in its 2012 TV advertising campaign, 'Let's End HIV'. Rob Lake, AFAO Executive Director, described the campaign as 'disconnected from a broad, sophisticated strategy necessary to promote safe sex and HIV prevention in the 21st century'.

'What we actually need is a fully-fledged campaign that engages with communities, improves dialogue and deals with the current realities of HIV prevention and treatment,' Mr Lake said.

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The logo for HIV Australia, featuring the word "HIV" in large, bold, blue capital letters above the word "AUSTRALIA" in smaller, bold, blue capital letters, all set against a solid orange background.

Got something to say?

Your views are important to the success of this publication.

HIV Australia publishes letters and contributions from readers. If you want to respond to something you have read here, or have an idea for an article, please write to us at: editor@afao.org.au

INTERNATIONAL

Appointment of new HIV ambassadors

Foreign Minister, Bob Carr, has announced the appointment of James Gilling as the new Australian Ambassador for HIV/AIDS, Tuberculosis and Malaria. Gilling replaces Murray Proctor, Australia's Ambassador since 2007.

'This role shows Australia's commitment to fighting HIV/AIDS, tuberculosis and malaria,' Mr Carr said.

The appointment was welcomed by AFAO. 'Given Mr Gilling's experience in foreign aid and development, we're confident he will be a strong advocate for prevention and treatment programs that target these three diseases,' AFAO Executive Director, Rob Lake, said.

UNAIDS has recently appointed Indian icon Aishwarya Rai Bachchan as International Goodwill Ambassador. In her role she will seek to raise awareness about stopping new HIV infections in children and advocate for increased access to antiretroviral treatment.

Commonwealth recommends repeal of discriminatory laws

Commonwealth Foreign Ministers recently announced they had accepted all the recommendations submitted by the Eminent Persons Group at the 2011 Commonwealth Heads of Government Meeting (CHOGM), held in Perth.

Significantly, Recommendation 8 calls on Commonwealth Heads of Government to 'take steps to encourage the repeal of discriminatory laws that impede the effective response of Commonwealth countries to the HIV/AIDS epidemic, and commit to programmes of education that would help a process of repeal of such laws.'

Discriminatory laws are widespread among the Commonwealth, with 42 of the total 53 Commonwealth countries

criminalising sex between men. AFAO and other civil society partners have been lobbying for Commonwealth governments to change discriminatory laws that undermine an effective HIV response by criminalising homosexuality, sex work and drug use.

Criminalisation discourages HIV testing: US research

HIV criminalisation drives stigma, discourages HIV testing, disclosure and access to treatment, and disproportionately impacts young people, according to a recent US survey of 2,000 people with HIV and 800 people from affected communities. Many of those surveyed believe that fear of prosecution makes it reasonable for people to refuse to get tested for HIV, disclose their status, or access treatment.

Nearly a quarter of those surveyed reported knowing one or more people who told them that they did not want to get tested for fear of being criminalised. More information at: <http://seroproject.com>

Criminalisation of HIV: Canada and Norway

Developments in Canada and Norway present a major blow to those campaigning for HIV to remain out of the criminal law arena.

In Canada, Supreme Court decisions in *R v Mabior* and *R v DC* entrench the requirement to disclose HIV-positive status prior to sex. The Court found that a 'significant risk' of HIV transmission triggers the legal duty to disclose. Contrary to public health understandings, the court decided significant risk is present unless a person has both a low viral load and uses a condom. (Decisions available at: <https://dl.dropbox.com/u/1576514/Mabior.pdf> and <https://dl.dropbox.com/u/1576514/DC.pdf>.)

In Norway, the Commission on HIV and the Law released their report, recommending only modest amendments to current practice. The Commission found that transmission is not necessary for there to be a crime and that undetectable viral load is

not a valid defence, although it may be a consideration in sentencing. The Commission addressed pre-sex disclosure (currently not a defence), recommending that it only be a defence if a partner truly consents to the risk of infection – an action that must be witnessed by a medical professional.

The Commission made one major concession, stating that no offence would be committed if 'proper infection control' measures are observed, such as condom use. It also stated that a single case of exposure, without transmission, would probably not be prosecuted unless there were aggravating circumstances, such as a person lying about their HIV status. (Summary of the Report available at: www.regjeringen.no/nb/dep/hod/dok/nouer/2012/nou-2012-17/18.html?id=705100)

Landmark transgender consultation

The 'HIV, Sexually Transmitted Infections and Other Health Needs of Transgender People in Asia and the Pacific' consultation, held in the Philippines on 11–13 September, was the first forum in the region to consider unmet and emerging health needs for transgender people.

Representatives from transgender communities, health professionals, researchers, the UN and regional agencies discussed a range of issues, including: the limited data on HIV and STIs among transgender people; stigma and discrimination; and the lack of transgender-specific communication strategies and health promotion materials.

The meeting agreed on ten recommendations and called for urgent mobilisation to create a safe, enabling, health care environment for the transgender community.

For more information see: <http://www.wpro.who.int/hiv/en>



It's time for a new approach to HIV prevention

By Jennifer Power

The Grim Reaper television commercial is infamous in Australia. Reminiscent of B-grade gothic horror flicks, the cloaked reaper stands in a foggy bowling alley poised to strike down a group of deadpan, but 'ordinary' looking, people. As the people are bowled down, a voice booms, 'at first only gays and IV drug users were being killed by AIDS, but now we know every one of us could be devastated by it'.

The Grim Reaper commercial appeared on Australian television in April 1987. It was a phenomenal marketing success. Some 25 years on, just about everyone who saw it remembers it. In my mind, the Grim Reaper was part of pre-bedtime viewing throughout my childhood. In reality, the ad ran for less than three weeks. I probably watched it only a handful of times.

The Grim Reaper has come to symbolise HIV/AIDS in Australia. It captured the fear and uncertainty of a time when people were not sure what would happen with this virus. It wasn't clear how large the epidemic might grow in Australia; there was certainly no sign of a cure and available treatments at the time were not particularly effective.

The Grim Reaper campaign was not without controversy. In some communities, gay men came to be associated with the Grim Reaper and were seen as a threat to the community, rather than being victims of the disease.

The campaign was immensely effective at drawing attention to HIV/AIDS. Politically this was important. The Commonwealth government had directed a lot of

funds toward HIV prevention and, although the Grim Reaper was not devised as a political tool, the response to it justified this spending.

The Queensland government has decided to resurrect the Grim Reaper imagery in a soon-to-be-screened television campaign designed to inform Queenslanders that HIV infection rates are again on the rise. The ad features an actor dressed as the Grim Reaper while the voice-over laments, 'we shouldn't be having this conversation'.

The Kirby Institute's 2010 Annual surveillance report indicates that in 2010 Queensland recorded its highest ever rate of new HIV infections, having

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more than doubled in the past decade, from 2.8 per 100,000 people in 2001 to 5.4 in 2010.¹

The Queensland government has responded to this with a new HIV strategy, beginning with the Reaper ad. But at the same time, it has withdrawn funding from the Queensland Association for Healthy Communities (QAHC, the former Queensland AIDS Council) – the very organisation that leads HIV prevention targeting gay men in Queensland.

In Australia, the vast majority of HIV transmission occurs between men who have sex with men. This has always been the case. While heterosexual transmission accounts for several hundred new diagnoses each year, a large proportion of these occur among people who have come to Australia from high-prevalence countries, or whose partner does.

A population-based HIV prevention campaign makes no sense if the flip side includes withdrawing funding to the organisation that targets people most at risk.

The government argues that defunding QAHC was a response to rising HIV rates – evidence of QAHC's lack of effectiveness – not an anti-gay agenda.

But it would be a concern if HIV prevention in Queensland was to become more conservative, with little acknowledgement of the needs or interests of gay men.

Australia is known as a world leader in HIV prevention largely because the federal government at the time had the foresight to see that community-led organisations such as QAHC were best placed to deliver targeted HIV prevention campaigns to the communities most at risk.

Alongside this, state and federal governments (for the most part) have resisted heavy censoring of safer-sex messages. Health educators have been able to talk openly about sex and produce sex-positive education campaigns. This has been more effective – particularly with lesbian and gay communities – than conservative or morally-driven strategies, such as abstinence education.

The Grim Reaper campaign worked at the time because of its shock value, and because it was accompanied by funding for targeted, community-led prevention campaigns.

The recent rise in HIV rates has occurred in a very different context. A complex combination of issues

are contributing to increasing HIV infections, including 'safe-sex fatigue' or people's lowered perception of 'risk' in an era where antiretroviral treatments are so effective.

The Queensland government may have some success in putting HIV back on the public agenda. But debate alone will not curtail HIV infections. What's needed now are sophisticated prevention campaigns, driven by people and organisations, such as QAHC, that understand the complexities of HIV transmission patterns in Australia at this point in history.

A version of this article was originally published by *The Conversation* (www.conversation.edu.au) on 20 August 2012. Reproduced with permission.

Endnote

- 1 2011 surveillance data, released after this article was written, indicates that although HIV rates have risen nationally by 8.2%, in Queensland they have fallen by 8.3%. Queensland's rate of HIV diagnoses is now less than that of NSW and Victoria, calling into question the Minister's decision to defund QAHC on the basis of rising rates of HIV. See: The Kirby Institute. (2012). *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2012*. The Kirby Institute, the University of New South Wales, Sydney.

It is also worth noting that, in September 2012, Queensland Health removed all images of the Grim Reaper from its website, claiming the site was being updated to make space for upcoming promotions and campaigns; the 'Let's end HIV' video remains in place on the site.

Dr Jennifer Power is a research fellow at the Bouverie Centre, and author of *Movement, Knowledge, Emotion: Gay activism and HIV/AIDS in Australia*. (See *HIV's Australia's* review of the book on page 47.)

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Targeting rural inequities: current priorities for rural health

By Penny Haney and Helen Hopkins

National Rural Health Alliance

The National Rural Health Alliance (the Alliance) is made up of 34 national organisations representing rural and remote health interests, including health professionals (nurses, doctors, pharmacists, dentists, paramedics and a range of allied health workers), health educators, researchers and students, health service providers and managers, Indigenous organisations and health consumer networks. The organisations in the Alliance work collaboratively to improve the health and wellbeing of people in rural Australia.

The Alliance takes a broad view of health and is concerned with a wide range of health determinants, including social, economic, cultural and environmental factors. Research is increasingly showing that beyond medicines, doctors, nurses, nutritious food and healthy activity, a person's good health is largely determined by the community in which he or she lives: its infrastructure, services, educational facilities, employment opportunities, capacity for personal interaction and social inclusion, and the extent to which its members have control over their lives.

Currently rural people face an annual health care deficit of at least \$2.1 billion, and a range of other inequities. At the annual face-to-face meeting of Council in September 2012, the Alliance set eight priorities for rural health. These are: to help reduce smoking rates in rural areas; to work for better oral health; high-speed broadband; HECS reimbursement for nursing and allied health (as well as medicine); Medicare Locals needs assessments and Healthy Communities reports that target rural inequities; healthy ageing and aged care in rural and remote areas; better mental health services; and quad bike safety. These priorities and their importance in implementing health reforms that work for rural people are discussed below. The Alliance would welcome further information from the readers of *HIV Australia* about the relevance of these issues to their own rural networks or of other key issues for rural health.

As well as finding constructive ways to raise current priorities with governments, the health sector and the public about key issues that must be addressed to achieve our common goal of equal health for all Australians by 2020, the Alliance hosts collaborative

public forums and seminars with other policy and advocacy organisations. For example, this year the Alliance co-hosted the National Oral Health Forum in August, the 3rd Rural and Remote Health Scientific Symposium in June and the Joint Policy Think Tank on national health reform in rural and remote areas in April. All submissions, fact sheets, publications, proceedings of seminars and conferences and so forth are published on the Alliance website, www.ruralhealth.org.au

The 12th National Rural Health Conference to be held in Adelaide from 7–10 April 2013 will provide a great opportunity for more than 1,000 people from all round Australia with an interest in rural health, to add their voices to recommendations for improving rural health.

Some current priorities for rural health

Preventing chronic disease: smoking as a sentinel issue

Improvements in health status and life expectancy for rural people are not keeping up with those in Australia's major cities.

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The Council of Australian Governments (COAG) Reform Council¹ reports that, in 2008–09, whereas 17.6% of people in the major cities were smokers, the figures were 27% for outer regional areas and up to 35% for remote and very remote areas. Unless the smoking rate in rural areas is reduced, Australia will not meet its national target to reduce smoking rates to 10% by 2018.

Urban-centric strategies often don't work well in rural and remote areas. The Alliance believes that the Australian National Preventive Health Agency (ANPHA) should devote a significant proportion of its resources to the particular challenges of preventing chronic conditions in rural and remote communities – commensurate with the extent of health need.

The Alliance is confident that finding ways to reduce rural smoking rates will have important lessons for health promotion and illness prevention for a range of other health risk factors and chronic conditions that contribute to the greater burden of disease in rural and remote communities.

Oral health

The oral health measures announced in this year's federal Budget and in August 2012 are very welcome. Having fully funded on-budget programs targeting children and low income adults will

place oral health services on a firmer footing than has been provided to date. However, no real progress will be made in improving oral health for people in rural and remote areas unless there are adequate numbers of dentists, therapists and hygienists in those areas.

There are also some concerns about putting the new children's and low-income adults' programs into practice. For one thing, successful implementation will need to involve more collaboration between public dental services and private practitioners.

There is also uncertainty about how the new system can cater properly for the dental care needs of elderly people who make up a growing proportion of the population in rural areas, including those in residential aged care facilities.

The States and Territories must be encouraged by every means to meet the quite evident public demand for improved oral health services by maintaining their own financial effort.

Broadband

High-speed broadband is essential infrastructure for households, businesses, services and health. By whatever means, people in all parts of Australia should have access to high-speed broadband at the same affordable price.

The Alliance is pushing for special programs to enable broadband connection early for those with the greatest need, such as families who are geographically isolated, Aboriginal and

Torres Strait Islander communities, and people with a disability. These programs would provide support through Regional Development Australia Committees or community organisations for people with high needs to get through the application process, negotiate with internet service providers and complete installation.

Medicare Locals needs assessments and Healthy Communities Reports

The next priority is support for making the needs assessment reports by Medicare Locals public and ensuring the Healthy Communities Reports² monitor how well needs are met within their area, as well as in one Medicare Local compared with another. Local people will then be able to be closely involved in the priorities of Medicare Locals.

The National Health Performance Authority is to produce Healthy Communities Reports for each of the 61 Medicare Locals – 26 of which have at least a substantial proportion of rural people. These reports will provide valuable evidence of health outcomes within and among Medicare Locals. They will also highlight the importance of data on health services and health outcomes – and show up the existence of gaps in the evidence needed to ensure improvements in health are being effected.

Workforce

Because of the shortage in rural and remote areas of both health positions and staff to fill them, some of the multidisciplinary health service models that might work well in more remote areas are not possible. Health services sometimes have to employ short-term contract staff at pay rates that seem excessive and are detrimental to the morale and tenure of permanent health professionals in the area. What is required is a local multidisciplinary team of health professionals who are flexible and able to work effectively.

Key members of these teams are nurses, midwives and allied health professionals. To increase the number

The Alliance would welcome further information from the readers of *HIV Australia* about the relevance of these issues to their own rural networks or of other key issues for rural health.

of these professionals in rural and remote areas, the Alliance strongly supports the recommendation from the recently-published Senate Committee Report³ that HECS reimbursement should be available to allied health and nursing graduates on the same terms as it is currently available for medical graduates. The Alliance recommended 20 steps including greater equivalence in incentives for recruitment, retention, placements and training of rural health professionals across the board as part of improving rural health services and workforce.⁴

Mental health

There has been additional investment in mental health services, including through EPPIC (Early Psychosis Prevention and Intervention Centre) and Headspace. The effectiveness of these programs is limited in rural and remote areas by their 'central place' nature.

In addition, the challenges of providing mental health services in rural and remote areas due to the shortage or absence of GPs and of allied health professionals, illustrate the need for a quite different approach to the delivery of mental health programs through primary care.

One way forward would be a trial of supported primary mental health care teams in areas that have poor access to GPs and are at a distance from regional centres in which much of the new money is currently being spent. Such teams would include mental health nurses and psychologists. It would also be important to upgrade the skills other health staff to give them greater capacity to deal with mental health issues.

Aged care

The package of aged care measures under the banner Living Longer, Living Better is designed to improve the system for consumers. The new agencies involved (the Aged Care Reform Implementation Council, the Aged Care Financing Authority and the single Gateway to services) are no doubt going to be important.

However, these new administrative arrangements do not ease the day-to-day challenges facing the aged care sector in rural and remote areas. These challenges are mainly related to staffing matters and financial security for residential aged care facilities and community care; and serious shortages of resources and staff for aged care in the home. The rural aged care sector is seriously short of infrastructure and in some regions has to compete for staff and other resources with the mining sector.

It is to be hoped that the Aged Care Financing Authority will give particular consideration to the financial sustainability of residential aged care facilities and community care in rural and remote areas.

Quad bike safety

The Alliance strongly supports the *Mt Isa Statement on Quad Bike Safety* dated 3 August 2012. It calls for the Federal Government to mandate an Australian crush protection device design standard for roll over protection on all quad bikes, and for manufacturers to comply with safety design specifications.

Quad bikes are now the largest single cause of fatalities on Australian farms; 160 people have died in quad bike accidents since 2001.

Conclusion

The Alliance believes that people should have their essential health care needs met as locally as possible, irrespective of where they live. Essential services may include preventive health care; maternal, family and child health services; general hospital care; aged and community care; and end-of-life care, as well as primary care.

However, there will be times in many people's lives or situations when it is not practical for the necessary specialised expertise to be available locally. Further, until current health workforce shortages are addressed, stop-gap measures will be needed to improve or even maintain access in many rural and remote communities.

The Alliance is supportive of measures to improve access to health care for rural and remote people through measures such as outreach services, improvements to Patient Assisted Transport Schemes, telemedicine and other support for remote health service providers, so long as these work with and do not become substitutes for essential services as locally as possible.

The Alliance believes that rural Australians will be well served by Government adoption of a National Rural Health Plan to underpin the practical implementation of the National Strategic Framework for Rural and Remote Health. Such a plan would incorporate benchmarks, targets and programs. It should draw on the demonstrated capacity of rural Australia to develop innovative and effective services that are underpinned by community ownership and resources that are focused on local needs.

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Staying in: a postcard from Shepparton

By Abigail Groves

Shepparton, in northern Victoria, is the kind of town I think of as the heartland of Australia. A regional town built on farming, like Wagga or Dubbo in NSW, its main claim to fame is its canned fruits and vegetables – the ubiquitous ‘SPC’ brand. In the 1960s and 70s it grew rapidly, as the increasing number of cars made it the service centre of a prosperous region. It’s a place where people work hard, pay off their homes, and raise families. ‘A good place to raise kids,’ people say. Meaning: ‘It’s a bad place to be gay.’

Shepparton is where I grew up. When I lived there, in the 1970s and 1980s, there were no gays in the town. At least, not

that I was aware of. It’s fair to say that in those days my gaydar was not highly calibrated: I didn’t realise that Boy George was gay. My mother’s friends tittered that one of the hairdressers in town was gay (and no, it wasn’t Tim Mathieson). The idea that there might be real gay people walking among us was just beyond me. But even for a sheltered teenager, Shepparton seemed suffocatingly small and conservative. I followed the path beaten by so many kids from regional towns: I left as soon as I could.

I’ve visited Shepparton frequently over the years, mainly to see my elderly father. Now, I know there are gay men

and lesbians living there and I know there must be people with HIV. When *HIV Australia* decided to do an edition on people in rural and regional areas, I determined to try and find out what life is like for them.

‘We do have members in Shepparton,’ said Brent Allen, Executive Officer of PLWHA Victoria, ‘but none of them are out about their status’. Allen’s comment was much as I suspected. Outside metropolitan areas, the stigma around HIV makes disclosure virtually impossible.

Damien Stevens is a community development worker with Uniting Care

Cutting Edge, and works with GLBT young people. He could not refer me to any HIV-positive locals either. 'I'm not aware of any HIV diagnoses among the young people I work with,' he says, 'or among older gay men around town, either.' He adds, 'There are a few guys who have said things which suggest they might be positive, but I don't know'.

The picture that Damien paints of gay community in Shepparton appears bleak and isolated. There are a few active community groups, but no local venue. 'There are a number of beats around town, but there's no venue or regular gay night here,' he says. 'People go to Melbourne to party. You can be anonymous there. On the other hand, there's a regular gay night in Bendigo, and I know some guys go there. Bendigo is almost as far as Melbourne, so you might not expect them to go there. I think they like Bendigo because it's a different scene – quieter and less intimidating.'

On the other hand, the emergence of social media has transformed the experience of being gay in towns like Shepparton, making it much easier for people to find each other. 'Social media is big,' says Damien. 'My friends and a lot of the young guys I work with are on Grindr or on *squirt.org*.' Not that social media solves everything, as Damien goes on. 'If you log onto Grindr here, you might see twenty people,' he explains. 'In the city there might be hundreds. And often it turns out that you already know those twenty people, and they are online keeping an eye on what everyone else is doing. When there's fresh meat in town or someone is visiting, everyone notices.'

Associate Professor Jane Tomnay is Director of the Centre for Excellence in Rural Sexual Health. Her service works with other services, capacity-building around women's and migrant health, GLBT and Aboriginal health. She echoes this theme of disclosure and anonymity, and suggests that these concerns affect the heterosexual community too.

'The epidemiological data we have about indicates that levels of STIs are roughly the same as in Melbourne,' she says. 'But STI data tends to say more about access than of prevalence. If anything, I would suspect that levels of STIs are a bit higher.'

When I visited Shepparton in the 90s, I used to joke that there were two things you could not get there: a decent coffee, and a bulk-billing doctor. That doesn't say a lot for access to healthcare.

'Things are certainly better than they were, in that regard. These days there are a few medical centres that bulk-bill,' says Tomnay. 'But that doesn't mean that people will use them. In towns like this there is a perception about lack of confidentiality in health services. We know from experience that it's often more a perception than a reality, but it's an important perception, because it influences people's behaviour.'

'In Melbourne, for example, an 18-year-old girl can walk in off the street and get a sexual health test – it's free, quick, and anonymous. That's much harder here.'

However, Tomnay insists that there is nothing to suggest that there is a hidden epidemic of HIV occurring in Shepparton.

'We did have an s100 prescriber in the town until a couple of years ago,'

she said. 'But he stopped renewing his accreditation, and I think that was because he didn't have enough patients to justify it. My perception is that people with HIV from around here go to Melbourne to access services. Some might go to their local GP, with a shared care arrangement.'

Tomnay's view is confirmed by Tom Schulz, an infectious diseases physician who visits Shepparton fortnightly. 'In small towns, people just won't access sexual health services even if they exist, because of fears about privacy,' he says. 'But Shepparton is a middle-sized town, so some people will access services here and some won't.'

Schulz agreed with Jane Tomnay's assessment that people with HIV are more likely to travel to Melbourne. He says he has seen only a handful of patients with HIV in Shepparton, and most are gay men. 'Melbourne is two hours away, so yes, people with HIV will usually go there, to the Alfred or Melbourne Sexual Health. Often they will combine the trip with something else that they want to do, so they don't mind doing that.'

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'In small towns, people just won't access sexual health services even if they exist, because of fears about privacy,' he says. 'But Shepparton is a middle-sized town, so some people will access services here and some won't.'

Such is the life of people across regional Australia. When I was growing up, any serious or complicated health problem involved travel. Some of my earliest memories are of catching the train to Melbourne with my mother. Though that trip is a little easier than it was forty years ago, access to specialist health care hasn't changed all that much.

'The positive people I see,' he adds, 'are often the ones who are sick of travelling up and down to Melbourne. It's a very small sample, so it's hard to generalise about their needs, but they are pretty similar to the kind of patients I would see in Melbourne.'

Instead, most of Schulz's patients are people from newly-arrived migrant communities. Perhaps the most striking change that has occurred in Shepparton since I left in the mid-1980s is the growth of new migrant communities. It had long been home to Italian and Greek communities, but in the last twenty years Albanian, Iraqi, Afghan, Sudanese and Congolese refugees have settled in the town. One writer called Shepparton 'a model of how multiculturalism can work'¹.

During a visit in 2006, I walked into a kebab shop on the main street. Seeing an Afghan flag on the wall, I asked the owner, 'Are you from Afghanistan?'

He was very excited by this level of recognition. 'You've been there?'

'Um, no,' I answered sheepishly. I didn't like to admit that my knowledge of Afghanistan was limited to what I learned in a Year 10 geography class. His English was not great, but I understood that he was a refugee and had been in detention. When I imagined transplanted from Afghanistan to the wide, flat streets of Shepparton, I couldn't help wondering what he thought of us.

'So how do you like Shepparton?' I asked.

He paused for a moment and I could see that he was trying to think of a diplomatic reply. Smiling ruefully, he said, 'Well, is better than ...' he drew his finger across his throat to demonstrate what the alternative of remaining in Afghanistan would have held for him.

'Yes,' I gulped. 'Yes, I suppose it is.'

'There is a bit of racism around,' says Tom Schulz, 'so I would not like to

promote the view that refugees are bringing in diseases. That's just not the case. Refugees with HIV aren't allowed into Australia. That has changed a little bit in the last few years, but Australia would still only accept perhaps 20 refugees a year with HIV. I've only seen a handful of refugees with HIV in my whole time in refugee health.'

Schulz explains that most of his refugee patients have health concerns other than HIV.

'Often people don't speak English and their health literacy is poor. Sometimes they have been exposed to TB, and hepatitis B is endemic in some countries. Refugees have health screening as part of the visa process, so if they have problems they will get referred to us.'

'One of the exciting things that we are doing,' Schulz went on, 'is getting more into telehealth, so that we can link patients up with specialists in Melbourne by Skype. Not everything can be done by Skype, but it can be really useful, and a lot more convenient for patients.'

Talking to Schulz, I'm reminded of how much Shepparton has changed. And yet, in some ways, not changed at all. There are many places much more isolated than Shepparton, but those two hours to Melbourne can still seem a long way.

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He paused for a moment and I could see that he was trying to think of a diplomatic reply. Smiling ruefully, he said, 'Well, is better than ...' he drew his finger across his throat to demonstrate what the alternative of remaining in Afghanistan would have held for him.

Abigail Groves is a freelance writer and former policy analyst at AFAO.



Unique Territory: an overview of the HIV epidemic in the Northern Territory

By **Panos Couros**¹

There is nothing typical about the Northern Territory (NT). A region of vast dimension and diversity, it is the third largest Australian federal division. Despite this it is populated with only 233,000 people, making it the least populated state or territory in Australia², representing 1% of the total population.

The Northern Territory has two distinctive climate zones. The northern end (commonly known as the ‘Top End’) includes Darwin, Katherine and Nhulunbuy and has a tropical climate with high humidity and two seasons, while the desert centre of the country (‘the Centre’) is a semi-arid central area which includes Alice Springs, Tenant Creek and Uluru. All of the Northern Territory is considered regional or remote.

Due to the unique history of the Territory, the population demographics are different from the rest of Australia. Trading began here over 500 years ago with the people of what is now mainly Indonesia and PNG, and the diversity of culture has been an ongoing feature of the Top End ever since. More than 100 nationalities are represented in the Northern Territory’s population, with more than 50 organisations representing various ethnic groups.³ The 2011 Census shows that Indigenous Australian people make up 26.8% of the Northern Territory’s population.⁴

All of this basic demographic information helps us to understand how HIV has affected the Northern Territory since records began in 1985.

While in the early years of the epidemic the HIV notification patterns were in line with national trends, with gay men presenting as the foremost affected population, we have seen this pattern shift significantly – especially over the past 10 years. Figures published by the NT Department of Health in 2010 show that overall almost 60% of all diagnosed HIV cases in the NT were acquired through unprotected heterosexual sex, which is quite different compared to the rest of Australia at 27%.⁵ Also surprising is whilst the NT has the highest rate of

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Indigenous population per capita, there is a relatively low proportion of HIV exposure in these populations, being 8.5%.⁶

Compared to the national figures, a large proportion of cases have been diagnosed in primary health care or hospital settings and these also often fall outside of the recognised risk groups. The majority of heterosexual cases have been associated with the person having a sexual partner from a high prevalence country.⁷ In response to these figures, the Royal Darwin Hospital has recently introduced policy that recommends HIV testing to be conducted on all adults admitted by the Division of Medicine. A guideline released by the NT Department of Health on 4 September 2012 stated:

*In order to both improve individual outcomes, and reduce transmission to other people, an increase in HIV testing is needed. In keeping with this aim routine opt out testing for HIV on admission to all health facilities is now recommended in the USA, UK and France.*⁸

Whilst there have only been 203 notifications of HIV in the Northern Territory, proportionally this figure is 0.087% compared with the national rate of 0.14%.⁹ Currently most people with HIV living in the Northern Territory live in Darwin, with some in Katherine and Nhulunbuy and the remainder in Alice Springs.

There are currently no cases of Aboriginal people being managed in remote communities. Until recently NT prisons had a policy of mandatory testing for HIV and due to the high

rates of incarceration of indigenous people passing through NT prisons, this gave a reasonable indication of HIV rates in remote Aboriginal communities. Whilst mandatory testing has now ceased, in keeping the current national HIV testing policy, the prison health service is supported to provide access to routine testing with informed consent. Also, with high birth rates among indigenous women, the national recommendation that pregnant women be tested for HIV is practised in the NT. Overall the surveillance data continues to give us a clear picture that HIV remains relatively localised within these centers. Another large pool of HIV in the NT can be found in people arriving as either refugees or sponsored work visas, as well as in people travelling from Darwin to South East Asia.

Clinical services for HIV are delivered by the NT Department of Health's Sexual Health and Blood Borne Virus Unit, Centre for Disease Control. These are called Clinic 34 and are run out of clinics in Darwin, Katherine and Alice Springs. Staffing for the clinic includes a HIV nurse on a three day per week basis in Darwin and a sexual health nurse in Alice Springs¹⁰ and Katherine. There is one full-time doctor in Alice Springs and one full-time and one part-time doctor in Darwin. Attracting qualified medical staff is a real and constant challenge to the NT and retaining HIV specialists in the NT has been a consistent problem.

The Northern Territory AIDS and Hepatitis Council (NTAHC) is the main support service in the Northern Territory, with offices in Darwin and Alice Springs. The principle role of NTAHC is to provide care and support

for people living with HIV, often via a shared care arrangement with Clinic 34. NTAHC is at the forefront in the delivery of prevention interventions and community education programs to affected individuals and communities.

The specific challenges faced in the NT in delivering effective prevention messages are complex. In particular, communication strategies used with other jurisdictions may not work with the same effectiveness here due to the socio-demographic and geographic differences. Many online and print resources are developed with a specific target audience in mind, and this is not easily translatable to people in the Territory. Although this material can be disseminated, the reach and effectiveness of this information is still limited due to the uniqueness of our target audiences, and due to the fact that these external resources are not developed with our audiences or context in mind.

NTAHC has responded by producing bold pictorial in-house information and education resources, which began with the 'Keeping our Blood Strong' campaign launched in 2011.¹¹ This has met with wide praise from many of NTAHCs priority populations.

NTAHC provides services that are both responsive to community and consumer needs whilst addressing the emerging issues in HIV care and support. Our care and support services for people living with HIV respond to accommodation and housing difficulties; issues regarding stigma and discrimination and disclosure of HIV status; the need to establish and maintain primary and specialist care relationships; nutrition education; promotion of safe sex behaviour; and the need to reduce harms associated with injecting drug use. NTAHC also prioritises viral hepatitis (B and C) programs and activities. NTAHC delivers three primary needle and syringe programs (NSP), outlets the NT Sex Worker Outreach Project from Alice Springs and Darwin, and an Aboriginal and Torres Strait Islander Sexual Health Program.

Whilst mandatory testing has now ceased, in keeping the current national HIV testing policy, the prison health service is supported to provide access to routine testing with informed consent.

In both Darwin and Alice Springs the issues around low-income and accommodation are significant. The NTAHC Alice Springs Program Coordinator, Jyoti Jadeja, reports that stigma and lack of information around HIV are still major issues for people with HIV in Central Australia. She states, 'People who live in towns may have heard of HIV, while in remote communities their knowledge on HIV is almost nonexistent.'

NTAHC runs regular support groups for people living with HIV in Darwin in the form of weekly lunches and a quarterly event called Eat, Indulge, Connect (EIC). This event combines the novelty of a live chef cooking session around a dinner party with up-to-date nutritional advice from visiting HIV specialist dietician Jenny McDonald. The sessions have health themes, such as the renal system and kidney function; cardiovascular health; oral health; diet and nutritional – low income cooking. EIC has been steadily growing in popularity since its inception in 2011. In June 2012, Nurse Mim O'Flynn and Jenny McDonald joined forces with NTAHC to provide our first HAART to Heart/EIC session for people living with HIV.

Future challenges

An emerging concern among populations of people living with HIV is ageing, with most people utilising NTAHC's services being 50 years of age or over. We are seeing a considerable challenge for our ageing HIV population relating to primary care. Access to a good GP is becoming far more difficult, with only one GP in Darwin who has HIV experience and a handful of GPs who see HIV-positive clients for general physical health checks. This factor combined with the cost of travel to GPs in Darwin or Alice Springs poses some daunting prospects in terms of future access to health care for HIV-positive people. Compare this to life in Sydney or Melbourne where people have a choice of GPs that can deal both with specific HIV and general health issues, most people in the Northern Territory need

a separate GP for issues that are not HIV-related.

Craig Cooper, NTAHC's Executive Director, sees the growth area for NTAHC services focus on dealing with the ageing HIV-positive population. This will necessitate the development of strategies to deal with complex care and support needs such as out of home care or other care and support options. With an ageing population, an older HIV-positive population, advanced HIV disease, as well as other co-morbidities associated with living longer with HIV, this will be a challenging body of work as there is limited understanding within the health system about how to meet the needs of people living with HIV. To begin with, there will be low numbers presenting in acute and chronic hospital admissions, but over time this will become a large proportion of NTAHC's work.

How best to reach people unknown or disengaged from the health system also poses a challenge. These are clients who are not engaged with NTAHC or Clinic 34. The new hospital testing policy is likely to identify increasing numbers of late presenters. The challenge for Clinic 34 and NTAHC will be to have adaptive and accessible services that people living with HIV feel comfortable returning to in times of needs, especially when they're lost to follow-up.

Overall the situation in the Northern Territory presents a very different picture to many other parts of Australia and there is often an assumption that what occurs nationally – even at a regional or remote level – is then easily translatable or transferrable to the Territory. Because of the unique set of circumstances that shape the history

and demographics of the Northern Territory, the remoteness of many desert communities, and the unique multicultural mix that is found in the Top End – as well as its proximity to areas of high HIV prevalence – we see a different picture here. These differences are very important to consider whenever national strategies, in particular communication strategies, are being designed. This is unique territory.

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An emerging concern among populations of people living with HIV is ageing, with most people utilising NTAHC's services being 50 years of age or over.



Our Country Practice: effective service delivery with people living with HIV in rural areas

By **Suzi Quixley**

What distinguishes good practice when working with people living with HIV in rural areas compared with working with people in urban areas? This article is designed to provide a practical guide for HIV workers with limited experience of rural service provision.

In June 2012, Positive Life SA (PLSA) ran Rural.Life+ – a weekend retreat for rural positive people which brought together participants from throughout South Australia (SA). This article explores the processes we used to plan the event, what we learned, what we would do differently next time and how the issues raised by rural people living with HIV are informing our ongoing practice.

A 'rural friendly' approach to the practicalities

Two PLSA staff have previous experience of service provision with rural men who have sex with men (MSM)/gay men and rural young people which informed our approach to planning Rural.Life+.

Rural.Life+ was run in Adelaide, rather than in a regional city. HIV-positive people told us that they preferred the event to be held in Adelaide for two reasons: because of the social attractions of a weekend in the city, and because it reduced the risk of being seen by someone from their local community and being 'outed'. We timed the weekend to align with PLSA's quarterly

social event, Planet Positive, to enable participants to meet a wider group of positive people.

Most rural positive people on HIV treatments are required to come to Adelaide every three months to access their \$100 prescriber. People living some distance from Adelaide cannot complete their travel and medical appointments in a single day. They must choose between paying an airfare, or taking another day or two to drive and paying for accommodation. Most participants routinely bear these additional costs not borne by urban people living with HIV. These trips also raise privacy concerns, with employers and others wondering why the person takes such regular Adelaide trips.

Accordingly, PLSA chose to cover all the costs¹ associated with participation in Rural.Life+. This also included paying for partners' travel and oncosts, which we saw as a matter of equity. In practice, only one participant wanted to bring their partner – most saw the weekend as an opportunity to have a mini-break away on their own, to meet some of their own needs.

PLSA purchased state-wide rural newspaper coverage² to try to engage with HIV-positive people not currently involved with PLSA. Two new people contacted us as a result. Existing members also reported having seen the ads, and felt that these may have contributed to raising HIV awareness in local communities.

Very early in the planning process we engaged with the accommodation/venue management and visited the site to build a relationship which would allow us to negotiate appropriate privacy arrangements. As a result, reception staff were only given first names of the participants, and PLSA took responsibility for all potential damage liability so that people could remain anonymous and wouldn't need to give out their personal contact or credit card details. This allowed us to reassure participants about measures to protect their privacy.

The central role of individual contact

PLSA individually contacted all (36) rural members to promote the event and personally invite them to attend Rural.Life+. While this took a lot of time, it was well worth the effort. This individual contact increased the number of people who attended. Ultimately, only one person (with existing attachment to PLSA) registered for the event without an individual conversation.

A surprising number of participants said 'But I can't afford accommodation', or similar. This was despite the fact that all Rural.Life+ promotional materials emphasised that participation was free of charge – with meals, accommodation

and travel all covered. An informed guess is that four or five of the participants may not have registered on the basis of perceived cost alone, had we not made a personal phone call.

It is much harder to maintain your privacy in a country town than in the city. Many rural HIV-positive people are even more protective of their privacy than their urban counterparts. Most potential participants expressed anxiety, asking things like 'Is anyone else coming from ...?' Several were concerned about the possibility that someone might come from their town, city or region when they were unaware of any other positive people living near them. Some were relieved to find that no-one from their immediate vicinity had registered.

Another common question from potential participants was 'Is it only for gay men?' It was important to keep all interested people individually up-to-date with the gender and sexuality mix of the group, so they could make their own decision about whether or not to attend. Ultimately, no-one withdrew their registration due to the mix – eight of the men identified as gay or MSM, and one as straight – however, it was important that they felt they had a genuine right to change their mind about attending at any time. During the weekend, all participants consistently reported that being part of a 'mixed sexuality' group was not a problem.

Most country HIV-positive people have mainly straight local friends, and those who are 'out' access most of their support from straight friends.

Many potential participants indicated some scepticism about the value of the weekend for them – particularly those who were relatively healthy, working and leading active lives. They responded best to information about the topics to be covered – particularly the opportunity to access new and relevant information on HIV treatments. We also mentioned the social and emotional benefits of connecting with other rural HIV-positive people – in a relaxed, peer-based (rather than a therapeutic) setting.

Others told us they were unable to attend Rural.Life+ due to other commitments. We took an attitude of optimum possible flexibility about people's attendance and spent a lot of time negotiating around individual needs. Often this involved identifying the parts of the program which were core to the event and the parts that were less central (both for the group as a whole or particular individuals). We also talked about how 'coming and going' affects overall group culture and interaction. In the end, most participants rearranged their plans

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in order to participate in the whole program. Those who could not do this were very respectful in the way they moved in and out of the group. PLSA also adjusted practical arrangements (such as paying petrol for three trips in lieu of accommodation, for someone from the near country who needed to check their animals daily).

Who participated in Rural.Life+?

A lot of thought went into how far to involve partners of HIV-positive people. It was ultimately decided to open the workshop itself to positive people only. Partners were welcome to dinner each night and Planet Positive on the Friday night. We also offered the option of a daytime activity for partners to get together, however this was not needed.

We found that a residential weekend away with other HIV-positive people is not attractive to all rural people living with HIV. In fact, 16 of the 36 eligible people in SA would probably not attend an event such as Rural.Life+. Of these people, seven clearly stated that they were unlikely to be interested (now or in the future), and a further nine people did not respond to our attempts to make personal contact.

On the other hand, 11 people registered for Rural.Life+ (with two having to withdraw due to work commitments). A further four people demonstrated strong interest in attending, but were unable to attend on that particular weekend due to work, social or family commitments. The remaining

five people were mildly interested. Ultimately nine men participated in the weekend.

What we did well ... and what we'd do differently next time

'A really fantastic weekend. I left it buzzing and feeling totally alive. It was great to be among others with similar experiences.'

'Very informative weekend ... I think we all came away feeling a lot better about ourselves.'

'I found the weekend to be informative, diverse, friendly and helpful in sharing issues relating to being vulnerable and isolated in rural communities. We listened, we laughed, we talked a lot, and we left feeling good about ourselves.'

'Thanx for a fabulous weekend, so rewarding and beneficial, met so many nice friendly poz guys.'

These were typical comments from Rural.Life+ participants – in fact, no negative comments were received about the whole event! So what made this weekend so effective? In addition to the preparation detailed above, five elements stand out from the participant feedback:

1. The majority of workshop time was allocated to discussion – of the realities of living with HIV; issues with accessing medical and support services; and the social realities of HIV disclosure in country areas.
2. Low intervention, flexible facilitation was used to keep people

on track, whilst not undermining the opportunity for conversations to 'take on a life of their own'.

3. The program was adjusted in response to the priorities and needs of the group.
4. Input was scheduled on only two topics – updates on the latest HIV treatments information, and the legalities of HIV disclosure (by the national HIV/AIDS Legal Centre [HALC]).
5. Evening social activities were integral to the program rather than an 'add on'.

Participants were evenly divided on which aspect of the program they found most valuable – the discussion time, input or social events. Participants also responded well to the fact that the program finished with (late) Sunday lunch. This allowed sufficient travel time for people to arrive home by early evening.

The program was adjusted in situ in response to participants' social needs. With limited opportunities to come to Adelaide, several participants needed shopping time. Others found the Saturday (9–5) program too intense and needed a break. We extended Saturday lunch, with participants free to either go off alone or attend an exhibition of art by positive people in a nearby Adelaide café. Participants returned refreshed and happy to continue until 6pm.

Next time, we'd plan a socially-oriented break in the middle of the Saturday. We would also finalise the date of the weekend and promote this much earlier. Several people were very keen to attend the event, but had pre-existing commitments. Six months' notice of a 'diary date' may have increased the number of Rural.Life+ participants by four to six people.

**'A really fantastic weekend.
I left it buzzing and feeling totally alive.
It was great to be among others with
similar experiences.'**

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HIV Rural Road Show 2012: issues of disclosure in rural and regional New South Wales

By **Lance Feeney** and **Melissa Woodroffe**

Background

Throughout 2012, Positive Life NSW hosted a series of HIV Community Forums in Regional NSW and Sydney. The National Association of People Living with HIV/AIDS (NAPWA) and the HIV/AIDS Legal Centre (HALC) agreed to join the program and the Community Forums aimed to provide up-to-date information on the current health and treatment issues for people with HIV, identify barriers to achieving good health and identify gaps in local services.

Program areas included:

- ageing, HIV and other health conditions
- an overview of new research on the health and transmission benefits of highly active antiretroviral therapy (HAART)

- information about new Medication Access Schemes in NSW
- HIV-associated legal issues
- regional and rural issues.

This article highlights some of the issues that were identified during the forums, in particular the concerns raised by HIV-positive people in regional areas connected with attending a community forum where their HIV status would be known to other participants.

Participants identified a range of issues experienced in a regional or rural area. Many participants described a shortage of specialist GPs able to prescribe HIV medications in their local area. People also said they had difficulty maintaining continuity of health care, having to regularly change providers due to the frequent turnover of GPs in rural and regional areas.

While rents are cheaper than in metropolitan areas, participants said that other costs (such as food, and car costs) are more expensive. Most people in regional/rural areas have to travel by car, and the cost of maintaining a private vehicle is difficult for those on limited incomes; public transport is also costly and services are limited.

Not all people in regional/rural areas have access to a computer or can afford internet services. Internet speeds are slow in many areas and this affects download speeds and ease of accessing information when surfing the net.

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It is important to note that many participants also commented on the significant benefits of living in a rural and/or regional area; including the slower pace of living, lowered stress levels, cheaper rents and more personal time available to them.

Fear of disclosure

The main issue that arose from all except the Bangalow forum was a reported fear of disclosure of HIV status to other community members as a result of attendance at the forums. Fear of HIV disclosure and being 'outed' within the local community and to family members was confirmed by service providers as a common reaction amongst rural and regional people with HIV, particularly among Aboriginal and Torres Strait Islander people.

HIV-positive women in regional NSW generally expressed fear of anyone knowing their HIV status. Some HIV-positive heterosexuals said they preferred not to attend forums that they perceived as being exclusively for gay men with HIV.

Forum participants reported the steps they took to preserve their confidentiality. Some preferred to travel to a sexual health clinic or hospital pharmacy some distance away from their home location because of concerns over family and/or friends working at the local clinics becoming aware of their HIV status. In some cases, people said they were prepared to travel up to 400 kilometres to obtain confidential clinical care and HIV medication.

Specific issues by region

Dubbo

There was very low attendance of HIV-positive people at the Dubbo forum, but a notably good attendance from local sexual health clinic staff. The HALC solicitor was able to meet with several people with HIV on a one-to-one basis at the sexual health clinic separately from the forum. These clients indicated that they were not willing to risk disclosing their HIV status to others by attending the community forum.

Sexual Health Clinic staff who attended the forum reported a similar reluctance of clients to attend sexual health outreach clinics because of fears that clients would be seen attending the clinic and that assumptions would be made about their HIV status.

The Dubbo forum presented an opportunity to talk with sexual health clinic staff about the latest health and treatment research. It also presented opportunities to discuss strategies to modify preventable risk factors in developing age-related health conditions, and to discuss access to HALC services. Discussions about the legal responsibility of health care providers to adhere to professional standards of conduct provided a better understanding of disclosure in health care settings and privacy protections, more generally.

Tamworth

There was similarly low attendance of people with HIV at the Tamworth forum but a number of local sexual

health clinic staff participated. Local service providers, who had spoken with potential participants, provided feedback as to why clients chose not to attend the forum and in addition to the general issue regarding fear of disclosure; a number of additional reasons included:

- **Access issues:** more than 50% of Tamworth Sexual Health clients live outside Tamworth. Some clients live a very long distance away from Tamworth.
- **Weather:** the forum was held in July, in very cold weather. In outlying areas, especially to the north, the winter is extreme – 'miserable'.
- **Issues of Aboriginal identity:** some Aboriginal and Torres Strait Islander people are reluctant to engage due to a complex range of issues. The community is small and breaches of confidentiality via gossip are reported as problematic. Other conflicting priorities include family and social responsibilities. Amongst Indigenous clients there may have been a perception that the forum was a 'white' event.
- **Workforce/care issues:** Many people are caring for families and have social responsibilities. Attending a forum is yet another imposition on their time.

Bagalow

The reluctance of participants to attend a community forum for HIV-positive people in Tamworth can be contrasted with comments from the participants at the comparatively well-attended Bangalow forum. Twenty-three people from the local area (Lismore and surrounds) attended this forum. This difference might be attributed to the relatively high number of people with HIV and people who identify as LGBTI residing in the Lismore area, many of whom relocated from Sydney. Lismore and surrounds has a very high LGBTI population and is often referred to as the 'rainbow region'. This difference in engagement may also result from higher levels of community

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connection and from social support programs run by ACON's Northern Rivers branch, located in Lismore. A number of participants commented on the value of such forums in terms of networking with other HIV-positive people from the local areas.

HALC has previously held community legal education sessions in the Lismore and Tweed Heads region with sexual health clinic staff and people living with HIV. These sessions have also been well attended.

It was encouraging to note that during the forum a number of participants commented on the valuable holistic approach taken by their HIV doctor in Lismore and by staff at ACON Northern Rivers. Participants reported that their treating specialist and other service providers had assisted them with referrals to HALC for legal problems, and to ACON for assistance with housing issues, for example.

Albury

The Albury forum was cancelled due to low registrations. Fallout from the Coroner's Inquest into the death of a gay man from the region in November 2011 – see the article by Iain Stewart Brady on page 33 – continued through the period when the forum was scheduled. The reporting in local papers about the HIV status of witnesses before the inquest (many of whom were also clients of a local Sexual Health Centre), caused high levels of distress amongst HIV-positive locals. It was therefore unsurprising that in such a climate, the incentive to attend the forum was low.

Newcastle

The main issue that arose from the Newcastle forum was the discriminatory behaviour of the staff at the venue toward participants. The forum venue was a GLBTI friendly hotel in Newcastle and the room where the forum took place was adjacent to the venue's kitchen/servery. During the forum there was a lot of background noise from the kitchen; however, of

greater concern was the unhelpful, unaccommodating and discriminatory behaviour of the kitchen staff.

As the forum progressed, the staff became increasingly hostile and aware of the HIV-related issues being discussed. Noise levels increased with what appeared to be deliberate attempts to disrupt the forum. One participant advised that kitchen staff were heard to exclaim 'they have AIDS!', and laugh.

These comments are stigmatising, discriminatory and unacceptable, and are at odds with the venue's claims as being 'GLBTI friendly'. Positive Life NSW has complained to the venue and has apologised to participants.

Conclusion

The forums provided a valuable opportunity to engage with and provide support, information and advice to people living with HIV in rural and regional areas of NSW. People in rural and/or regional areas face increased isolation and lack of access to support services in comparison to those residing in the inner-city or suburbs of Sydney. The forums were intended to develop and enhance the links between people with HIV and Positive Life NSW and its partner organisations, as well as provide opportunities for HIV-positive individuals in regional and rural areas to network and share information with others.

Despite the small number of people at some of the forums, the program was well received by those clients

and service providers who attended. Respondents to the evaluation survey clearly valued the opportunity to participate in the forum and thanked Positive Life, NAPWA and HALC for organising the event. Participants found the information discussed useful, appreciating the frank discussion and the value of hearing other clients' points of view. Some service providers reported that the forum provided a valuable professional development opportunity and that they were now more confident in referring clients to other services (such as HALC).

The experiences of running these forums and the important feedback gathered highlights the challenges faced by Positive Life NSW, NAPWA (the National Association of People Living with HIV) and other support organisations in their ongoing efforts to engage with rural and regional populations. Clearly different approaches are required to meet the needs of people with HIV in these regions. Positive Life NSW and partner organisations are considering a range of engagement options to address these issues.

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Developing regional responses to HIV in the era of combination prevention

By **Dermot Ryan**

Although the majority of the population in NSW live in Sydney, it is not surprising that many regional and rural communities are scattered along NSW's magnificent coast line. The majority of infrastructure is based along the coast, affordable housing is often available, and public transport is more accessible. There are also greater employment opportunities along the eastern seaboard, as well as more options for community participation.

The majority of people affected by HIV in NSW are gay men, with the largest gay male population located in the inner Sydney area; in fact, around 25% of Australia's HIV-positive population lives in or adjacent to the South Eastern Sydney Local Health District (SESLHD).

Smaller but significant communities of people living with HIV, gay men and men who have sex with men (MSM) are located in the major coastal regional centres of Newcastle and the Illawarra, with population pockets in the Mid North Coast and Far North Coast areas.

This year there has been momentum towards including the targets set out in the United Nations 2011 Political Declaration on HIV/AIDS (UNPD) into our collective response to HIV.¹ These include: reducing the sexual transmission of HIV among gay men and men who have sex with men; reducing transmission among injecting drug users; sustaining the virtual elimination of mother-to-child transmission; sustaining the virtual

elimination among sex workers; and increasing the number of people living with HIV on antiretroviral treatment by 2015. Initiatives to achieve these targets include increasing community access to improved HIV testing technologies, and improving access to HIV treatments for people living with HIV by acknowledging and addressing barriers to the supply of medications.

In 2011, approximately 10% of HIV diagnoses notified to NSW Health and recorded in surveillance data were among people living outside the wider Sydney area. The majority of these were located in just a few key rural areas, mainly on the NSW coast north of Sydney. ACON provides services along the coast of NSW, with a presence in the Illawarra, Hunter, Northern Rivers,

Port Macquarie and Coffs Harbour. The concentration of people living with HIV and our target populations for HIV prevention education (gay men, MSM, injecting drug users and sex workers) in inland NSW is low, and direct services to people living with HIV focus on primary health care delivered through NSW Health Clinics; however, ACON provides outreach services as needs are identified.

ACON regional offices provide client services, health promotion and counselling programs along with a variety of other community development and education programs based on local community needs. For example, HIV Health Promotion programs specifically targeting HIV-positive gay men are delivered by ACON in the Northern Rivers where a significant population of people living with HIV has resided since the epidemic first emerged in Australia. In the Hunter, ACON has provided alcohol and other drug-related therapeutic services and counselling. More recently, the Sex Worker Integrated Care Coordination Project has been delivered to address the health, wellbeing and safety issues faced by street-based sex workers in the Islington area.

Across most Australian jurisdictions, the Gay Community Periodic Surveys (GCPS) provide an important set of behavioural data to inform HIV prevention strategies. The survey provides information on gay men's sexual practices, drug use, and testing for HIV and sexually transmissible infections (STIs). Surveys have been conducted, generally in metropolitan settings, across six Australian states and territories since 1996.²

Town and country: comparing risk behaviour between rural and urban gay men

In 2009, ACON's regional services collaborated with NSW Health, three regional HIV and Related Programs (HARP) Units of the then Area Health Services and the National Centre in HIV Social Research (NCHSR)

in a one-off research project which applied the GCPS approach to regional settings in NSW. The aim was to identify similarities and differences in risk behaviour between rural gay men and MSM, and their city counterparts. The findings were reported in a number of ways, principally in *Town and Country*, published by NCHSR.³

The research compared survey responses of 1,371 men recruited for the Sydney GCPS in August 2009 with responses of 469 men recruited for a survey of gay men in regional NSW between August and November 2009. The data compared these two groups of men (from the city and regional areas) on a range of risk indicators.

A key finding of *Town and Country* was that there was a much greater degree of similarity than there was difference between the two groups. While it is important to understand the differences and what impact they may have in developing appropriate regional responses to HIV prevention and HIV health promotion, it is just as important to note that in a regional context, much of the data from the Sydney GCPS is highly relevant and applicable for rural gay men and men who have sex with men. This regular data source can be useful as a planning tool for delivering services to gay men and MSM, including those with HIV.

Some of the key similarities highlighted in the report are summarised here:

- Gay men in regional NSW and Sydney were equally likely to:
 - have a boyfriend/regular partner (~½)
 - be recently tested for HIV (last 12 months), if they have previously tested for HIV
 - use condoms (or have unprotected sex) with casual and regular partners
 - tell partners their HIV status (disclose)
 - meet men at beats, dance parties, private sex parties and through the internet or sex workers.

Some of the key differences highlighted were:

- Gay men from regional NSW are more likely than Sydney men to be:
 - under 25 or over 50 (more younger men, more older men)
 - involved in the local gay community
 - introduced to partners through friends
 - in a relationship with a man of untested/unknown HIV status
 - in a monogamous relationship.

continued overleaf

In 2011, approximately 10% of HIV diagnoses notified to NSW Health and recorded in surveillance data were among people living outside the wider Sydney area. The majority of these were located in just a few key rural areas, mainly on the NSW coast north of Sydney.

- Gay men from regional NSW are less likely to:
 - have ever been tested for HIV (89% vs. 93%)
 - be recently tested for STIs
 - meet partners through gay venues (bars, gyms, saunas)
 - have high numbers of casual partners.

These findings reflect the experience of many service providers in regional and rural areas who identify that some gay men will leave rural areas to obtain employment or further their careers and will retire to rural areas later in their lives. Gay men in rural NSW are less likely to meet partners through a gay venue, which is hardly surprising given the much greater concentration of gay venues in the inner metropolitan area. Other survey data highlights the need to address lower HIV and STI testing rates among gay men in rural NSW by providing incentives to deliver campaigns to increase testing. To achieve testing targets, education campaigns and better access to modern and user-friendly testing technologies will be required.

Organisational partnerships to increase testing

ACON's regional offices have Memoranda of Understanding (MOUs) with a number of local

community and health partners. MOUs with Local Health Districts establish the framework for developing and maintaining effective partnerships that work to improve service delivery to the community and to specific populations. These local partnerships have enabled innovative responses to achieve shared goals. Such responses have included provision of regular sexual health clinics offered from some ACON regional offices. These clinics have provided sexual health testing for a number of years. Collaboration with local sexual health services developed through the MOU framework means that clinic access is increased and offered from a community setting.

The recent introduction of rapid testing services at four NSW Health Sexual Health Clinics in Sydney is heralding a new age of testing access and availability in Australia. While these rapid testing services are currently trialling, they represent an important advance in the HIV prevention response in NSW and across Australia. A challenge for our regional and rural services will be to ensure that such rapid testing technologies are also offered as a standard part of service delivery.

Barriers to regular testing include inconvenient service hours, limited access points, and lack of access to

newer testing modalities such as express clinics, and provision of same day results. The impact of travel to services in regional and rural areas also needs to be considered. The lack of equity in accessing testing services between capital cities and regional and rural areas requires immediate and effective action. Limiting rapid testing to capital cities would potentially widen the gap in testing levels between city and rural gay men and other MSM. When the impact of travel is considered, the option of home testing with online support starts to look very attractive – from both a convenience and a funding perspective.

Regional and rural areas need to create, and be a part of, developing innovative responses to improving HIV testing, including opportunities to be included in existing and future trials. Initiatives should include utilising the existing community-based outreach clinics, and take advantage of community events and festivals as possible testing venues. It is early days, but regional and rural communities do not want to miss out on capitalising on the current advances.

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Other survey data highlights the need to address lower HIV and STI testing rates in rural NSW gay men by providing incentives to deliver campaigns to increase testing. To achieve testing targets, education campaigns and better access to modern and user-friendly testing technologies will be required.

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Telehealth in general practice: providing alternative access options for people in regional, rural and remote areas

By **Joanne Hereward**

In 2011 the Australian Government introduced a range of rebates through the Medicare Benefits Scheme (MBS), and other financial incentives, to support telehealth video consultations between a patient and a GP in the same location and a specialist in another location.

The Royal Australian College of General Practitioners (RACGP) is playing a leading role in supporting telehealth as an alternative option to physical consultations, where it is clinically justifiable and where it enables more convenient and accessible health care delivery without compromising patient care.

Telehealth video consultations have been around for a while in the hospital sector. Affordable software technology and the Medicare Benefits Schedule (MBS) rebates have made it possible to introduce telehealth services into primary healthcare. The benefits of

telehealth are extensive, providing better access to specialists for patients who live in outer metropolitan, rural and remote areas, and those in eligible residential aged care facilities or Aboriginal medical services anywhere in Australia.

People want to have more control over their healthcare and they want to do this with healthcare providers they know and trust. Many patients have a good and longstanding relationship with GPs in their local community. Video consultations can facilitate the provision of collaborative care, by the specialist and GP, without the patient having to leave their community and incur the costs and time associated with travelling long distances.

Telehealth services also provide GPs and other specialists opportunities for informal GP education, opportunities to clarify any patient

confusion or misunderstanding (early and effectively) and also improve peer-to-peer contact and discussion between GP and specialist.

Practice nurses and Aboriginal health workers can also provide clinical support to patients on behalf of a GP during a video consultation with a specialist.

The telehealth MBS items and financial incentives that are currently available make it an opportune time for GPs to implement telehealth services into their practices and offer telehealth consultations to their patients.

However, not all consultations will be suitable for telehealth and GPs need to consider a number of key areas when planning to offer video consultation services. The RACGP

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Standards for general practices offering video consultations: An addendum to the Standards for general practices (4th edition) covers the practical side of video consultations, such as setting up the consultation room to facilitate successful video consultations, as well as the issues surrounding patient privacy and confidentiality, and the training and education for practice staff involved in these consultations.

Implementing video consultations in a practice is a gradual process. Each general practice is unique and there are many technical, organisational and human factors that need to be taken into consideration to achieve a high quality video consultation.

The practice needs to provide the best environment for the consultation which includes the equipment, technology, and data connections to deliver the consultation. A key component of successful video consulting is selecting the appropriate technology, and it is advisable for the practice to trial a range of video conferencing software to find the most suitable one.

Telehealth video consultations also need to ensure that the patient's health and personal information is protected, and to ensure this, the consultation must be conducted in a technical environment that is reliable and has effective security measures in place. The RACGP *Computer and information security standards* offers comprehensive and up-to-date advice on the requirements to ensure the appropriate security measures are in place within the practice during the video consultation.

From an organisational and human perspective, there are many contributing factors to the overall success of the video consultation, including engagement with specialists, practice staff education and training in relation to new technologies and work processes, clinical and operational guidelines, managing change, monitoring mechanisms, and appropriate infrastructure.

An enthusiastic video consultation coordinator can also help enormously when implementing video consultations into a practice. Their responsibilities can include coordinating bookings, managing the video conferencing equipment and software, providing patients with relevant information, and ensuring there is a contingency plan for managing technical issues that may come up during the consultation.

The RACGP *Implementation guidelines for video consultations in general practice* (3rd edition), published in September 2012, provides practical and comprehensive advice on all aspects involved in offering video consultations including:

- setting up
- telehealth MBS item numbers and the range of telehealth incentives currently available
- information on which videoconferencing options for GPs and practices to consider
- the viability of implementing telehealth
- information on engaging with specialists, including a letter template to initiate contact with specialists
- advice on change management
- advice on using Skype™
- technical advice
- assistance with the end-to-end management/process of conducting the video consultation
- popular software video conferencing options and hardware options for clinicians to consider.

The RACGP offers a range of factsheets, resources, and templates, including a booking checklist, patient information brochures, an introduction to specialist letter, and a post-video consultation patient evaluation tool.

Another key question often asked in relation to video consultations relates to the use of Skype™. Currently there is no clear evidence to suggest that Skype™ is unsuitable for clinical use; however, there are issues that GPs and other medical professionals need to be

aware of before making the decision to use Skype™.

The RACGP recommends that GPs (and those providing clinical support on behalf of GPs) should register a Skype™ name that provides some anonymity. It is additionally recommended that, during a video consultation using Skype™, medical content is not exchanged (e.g. still images) and that there is a back-up mode of communication in case the connection cannot be made. Skype™ does not provide instantaneous technical support.

Skype™ should be considered as a low cost entry point to the world of telehealth. If selecting Skype™ initially, over time (and once the ongoing demand and usage of video consultations has been quantified) it may be worth considering moving to a professional software and hardware solution. The RACGP advice on using Skype™ provides more detailed and comprehensive information and can be found on the RACGP website at www.racgp.org.au

Decisions about offering video consultations should be made by individual practices and careful consideration should always be given to the needs of the patient and the viability of telehealth within the practice.

As part of the telehealth initiative, the RACGP has been funded by the Australian Government Department of Health and Ageing to provide a telehealth support service until May 2013. For further information, or to access a range of online resources, visit the RACGP website at www.racgp.org.au/telehealth or contact the RACGP telehealth support service on 1800 257 053 or via email at telehealth@racgp.org.au

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Making connections: investigation of an online counselling service for gay and same-sex attracted men in South Australia

By Ben Yi and Rob Willoughby

Background

The internet is increasingly used by people as a means to seek out health-related information.¹ Research findings in the United States suggest that more than a hundred million people (75% of all adults and 28% of all teens) per month use the internet to look for health-related information.^{2,3}

Technological advances have also largely expanded the ways in which many health services are delivered.⁴ Web-based health information and referral services are readily accessible and are continually gaining more popularity among users; some mental health professionals have already started online group work around mental and behavioural health issues.

The internet certainly presents a way to reach a range of individuals who are currently marginalised and isolated, either due to social stigma or geographic location.⁵ A wide range of web-based online services and e-programs targeting the LGBTI community are also emerging, and computer mediated communication could be increasingly used for counselling purposes to meet

the complex needs of these diverse communities.

With all of this in mind, we want to consider the ways online health services could eventually develop into a more interactive mode and allow therapeutic intervention, advocacy and support in an online counselling context. How can computer mediated technology build a pathway to deliver professional online counselling services to people who are both socially and geographically isolated in our community?

Rationale

Use of the internet in Australia is commonplace; in 2010–11, 79% of South Australian households had internet access, and 77% of these household members were using the internet every day.⁶

Gay and same-sex attracted men live in communities across South Australia, including in the country and geographically isolated areas. There are currently no identified counselling services in rural and remote areas of South Australia that specifically cater for gay and same-sex attracted

men. There are many barriers that can prevent gay and other same sex attracted men in rural areas from using local health services. In the counselling experiences of the AIDS Council of Australia (ACSA), these barriers may include: feeling embarrassed, uncomfortable or afraid when visiting health service providers; lack of trust in maintaining their confidentiality in a small community; differing health beliefs; distance and cost; lack of private vehicle ownership; and culturally inappropriate services. Online counselling could provide a potential platform that is peer-based and user-friendly and would be readily accessible to this client group.

Gay and same-sex attracted men living with HIV who are isolated both socially and geographically experience significant overlapping layers of stigma and discrimination.⁷ These men can experience discrimination restricting access to supportive health care because of their HIV status as well as their sexual identity, and

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this is further compounded by their physical and social isolation.⁸ This lack of accessibility to health services can impact on their overall physical and mental health and wellbeing.

In a 2008 qualitative study involving 16 general practitioners who treated gay and HIV-positive men, social isolation was found to be a significant factor contributing to their patients' overall health status.⁹ Other evidence reveals a high prevalence of major depression and suicidality among these isolated groups.¹⁰ Establishing an online counselling service that people can access in a space where they feel more comfortable to talk through their issues would be beneficial.

In practice, text-based messaging tools (such as Skype™, Microsoft Messenger (MSN)™ and so forth), as well as email, have been widely used for counselling purposes; instant messaging tools provide synchronous conversations in real time, while the use of emails may allow asynchronous communication and provide a client with sufficient time to respond.¹¹ Online counselling services can transcend of the limitations of time and distance and can be accessed when and where the client chooses.

Feasibility: potential challenges?

As always, there are two sides to the coin: online counselling presents some challenges that we need to acknowledge and confront, such as issues around non-verbal communication and confidentiality.

Counselling online using email and other text-based messaging tools represents a challenge in terms of a lack of visual and auditory cues. These non-verbal cues often offer a counsellor implied messages around the client's ongoing feelings and emotions.¹² The absence of non-verbal feedback during text-based online counselling sessions potentially creates challenges for counsellors in making accurate assessments.

Confidentiality is also a major concern in the provision of counselling

services.¹³ It is often the case that a client who wishes to express deep inner feelings around ongoing sensitive issues or traumatic experiences may fear the consequences of accidental or deliberate disclosure of the shared information.¹⁴ Traditional face-to-face counselling provides more security in controlling information disclosure in a private and safe environment for a conversation, with password locked computers for e-records and confidentiality forms for signature. The counsellor can also potentially show the client information security measures such as locked cabinets for client's records.¹⁵

All of these measures in practice are likely to boost a client's confidence to share their issues. Counselling in an online environment may lack some of these secure components, since confidentiality relies largely on the computer security system which could be perceived to be vulnerable to a hacker's attack or other conditions that may lead to the loss of client's data.¹⁶ To ensure a client's information is well protected, encryption and authentication in online messaging and emailing systems need to be maintained and further developed.

Fee-based online counselling has been the tradition for most online professionals, both domestically and overseas.¹⁷ However, there are still concerns around the practicalities: how much should online counsellors charge? How safe is the payment process? What is the general affordability for the client group? Would such a service charge be an obstacle for clients' motivation for seeking help? A solution to this may be to conduct a survey of potential clients in order to clarify their opinions on these questions.

Conclusion

'The right dose differentiates a poison'¹⁸. We believe there's no 'black or white' answer for online counselling yet; it has to be operationally appropriate to ensure each client's online therapeutic experience is a positive one. The feasibility of online practice is an exciting prospect to explore based on more scientific research as well as an active engagement with the targeted community.

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'They're the ones that have a problem': living with HIV in a remote community

By Finn O'Keefe

David¹ lives and works in a remote town of the Northern Territory, where he has been based for many years. He has been living with HIV since 1985, and commenced antiretroviral treatment earlier this year with the support of two interstate doctors: one based in Sydney (who he has been seeing for over 20 years) and one in Melbourne. David got in touch with *HIV Australia* to share his story about his experiences of living with HIV in a remote community.

'Living in a small community – it is quite difficult, so I keep myself private. If for any reason it became public knowledge that I am HIV-positive I would be forced to leave the community and would not be able to work anywhere in the Centre.

'Out in the community you can't talk to anybody about [being HIV-positive] ... No one else will talk about it either. So I just keep to myself; you'd be excommunicated if anyone found out. There's still that fear factor out in these communities. And everyone talks, so it's just not worth it, trying to access services within remote communities ... it's just not worth the risk to your person.'

David says there is a scarcity of HIV services in remote areas, and there is little to no information about HIV available in local clinics. He says he has to travel long distances for appointments, and even then still experiences issues accessing services: 'I've found it pretty difficult living here, because every time I've come into town to the HIV clinic there's been no doctor – and I've driven hundreds of kilometres to come in and see somebody.'

'Like, I wanted to go and see a local doctor this week and I've rung up and was told: "Well, we don't have one available today. There's someone here

on a Tuesday afternoon and that's it." This gets very frustrating. It ended up taking me about two or three months to start medication; in the end I found it easier to go to Melbourne to start my treatment with the incredible support of a clinic there.'

David was 21 years old when he was first diagnosed with HIV. 'I'd actually never had anal sex before ... it was like "oh no!"

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'I had a boyfriend. We went and got tested because that's what everyone was doing. Actually, I'd had a test in Brisbane once before that, and was negative. Then I moved to Sydney and I was [diagnosed] positive within six months.'

'I cried for a week ... and then just decided: it's OK. You know what? It's just like getting a cold, just look after yourself; be aware of it. And that was it. And my Sydney doctor said, "Look, you're really, really healthy. You've got a really positive attitude towards it. Just keep an eye on it."

David explains that having a good relationship with your doctor is extremely important. Although he has not been able to disclose his HIV status to anyone in the communities where he lives and works, he says that his long-term treating doctor in Sydney has given him all the support he needs to remain healthy and maintain a positive outlook.

'I've had the same doctor for probably 20 years. And he's right up to date with HIV medicines. He does a lot of trials. He's in Sydney ... and he's always been available to me. He told me: "Just look after yourself, keep the right attitude." So I did. I made sure I didn't accept the disease as like, "Oh, why me? It's gonna kill me. Everyone hates me." I just went: "Nah, I've got a cold – it's fine. Just watch it. Look out for yourself."

David has been living with HIV for 27 years and has always been in excellent health. He explains why he only began antiretroviral treatment earlier this year: 'I went on treatments about six weeks ago. Finally. My T-cell [CD4] count has always been excellent (high 600s) and my viral load was always low, so I was really healthy. But then my viral went up to 110,000 and I was advised by a doctor in Melbourne to go on antiretrovirals.'

David says that he was initially very frightened about starting treatment because of the side-effects he had seen other people experience in the past. 'I thought, "I'm gonna be sick every day," because everyone used to get really sick on [treatments]. I think taking that amount of tablets was a constant reminder of "you're sick, you're gonna die," – that's what was always drummed into you.'

Following conversations with his doctors in Melbourne and Sydney, as well as discussions with staff at Northern Territory AIDS and Hepatitis Council (NTAHC), David was reassured that commencing treatment would be the best thing for him. He is taking a regimen of one pill a day and says is all going fantastically: 'I just can't believe it. Within three weeks my viral load had gone down to 460. It's probably undetectable by now – you know, after six weeks'.

Despite the difficulties David has experienced accessing care in his local area, he says he is able to maintain regular contact with his doctors in Sydney and Melbourne via the internet.

'I actually have two doctors now who collaborate with each other. And they're available to me online. So I can ring up and go: "Hey ...", and they've given me websites to go to. If I get prescribed another medication, I can go online and see if it reacts with what I'm already on. I don't have to divulge all my information in the community that I'm in, so it's extraordinary. And I don't have to travel.

'I haven't worked out, y'know, what to do if I get really sick. You don't want to tell the small community that you're in that you're HIV [positive] ... we haven't got that far yet. They are bringing in e-health in the Northern Territory, but I don't want to go on it because that will divulge my HIV status. I'd go to the clinic and they'd look at it.'

David maintains a very active life, and despite the stigma that forces him to keep his HIV status and sexuality a secret where he lives and works, he maintains an extremely positive outlook:

'I just don't see having HIV as a disability, you know? I think I did get depressed at one stage about it, many, many years ago. But it was dealt with. Now I have a full time job, I travel all over. I help people. I've always got a big grin on my face! It's not a problem. Being HIV [positive] is not a disability. It is – but it's someone else's disability ... not mine. They're the ones that have a problem.'

Reference

- 1 Identifying details in this article have been changed to protect David's identity.

David explains that having the support of a doctor whom you have a good relationship with is extremely important. Although he has not been able to disclose his HIV status to anyone in the communities where he lives and works, he says that his long-term treating doctor in Sydney has given him all the support he needs to remain healthy and maintain a positive outlook.

Finn O'Keefe is Communications Officer at AFAO and an editor of HIV Australia.



In regional NSW, slight cover from the harsh glare of 'Open Justice'

By **Iain Stewart Brady**

Fear of courtroom disclosure of a person's HIV status is always a concern, even in busy inner city courts where the hustle bustle means that matters can sometimes escape particular attention. In relatively sleepy regional courts, however, anonymity is impossible. The way practitioners and courts deal with HIV disclosure and suppression throws into sharp relief the jeopardy HIV-positive people can face in access to justice.

The HIV/AIDS Legal Centre (HALC) has been working on the issues of court suppression of HIV status and access to justice for some time. (See Melissa Woodroffe's article on Court suppression in *HIV Australia*.¹)

Fear of unwanted disclosure of a person's HIV status in court can prompt some individuals to decide not to place that information, though relevant, before the court. It can prompt others to abandon recourse to court at all, and so deny HIV-positive people access to justice and to protections under the law. When the court process is foisted

upon a person, with HIV writ large on the agenda of the court, the practical problems posed for HIV-positive people in obtaining justice and privacy are shown in high contrast.

Early this year, HALC was approached by a sexual health nurse from a regional centre. A local court hearing was underway concerning a suspicious death. Many of the people involved in the hearing were clients of the Sexual Health Centre and some clients had been called as witnesses. Most were gay men; some were HIV positive. It was suggested by the court that the HIV status of some parties was relevant to the hearing.

The hearing had already commenced when we (HALC) were contacted. Significant evidence had already been published in the local newspaper. The lawyers representing the main suspect had not sought suppression of the sensitive HIV information and the idea of suppressing names or other delicate and possibly extraneous evidence had not been raised until now.

The culture of 'open justice'

In NSW there is a very strong culture of 'open justice': the notion that as a rule, justice processes need to be transparent and public, above all other considerations. Although local court decisions are not published and obtaining court transcripts and records can be an obscure and Kafkaesque process, anyone can attend court and watch the play of courtroom theatrics. Having viewed the hearing, people are then at liberty to report, gossip and relay the information in public as they please.

Open justice aims to protect us from the tyranny of the Star Chamber – namely arbitrary, secretive proceedings and secret untested evidence and trials. It is argued that public airing of the information is a curative for crime and a protection from false testimony, as airing material which is false may prompt truth tellers to come forward and correct the record.

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This same robust culture of ‘open justice’ does not exist equally in all Australian jurisdictions. In Victoria, for instance, section 133 of the *Public Health and Wellbeing Act 2008*, provides that if evidence is proposed to be given in a matter before a court or tribunal of any matter relating to HIV, or any other prescribed disease, the court may be closed to the public, may restrict persons present from hearing the information and/or prohibit publication of the material. The main consideration for the court is the social or economic consequences to a person if the information is disclosed. Even in NSW, strong suppression provisions apply in relation to victim’s evidence in sexual assault matters.²

Victoria remains a strongly democratic jurisdiction despite the fact that it has legislated to allow closed courts in HIV-related matters. Protection of the vulnerable in court processes has been achieved without any appreciable loss of democratic freedom or corruption of the rule of law. Why can’t similar protections be made available in NSW?

Case study from regional NSW

At the time HALC was contacted about the NSW case, the media’s reporting of the hearing and evidence had already caused a great deal of anxiety and fear among the HIV-positive community and clients of the Sexual Health Service. In a small town, that kind of court hearing would raise considerable local interest anyway, but with the local gay community and HIV infection thrown into the mix the interest was amplified.

When we were contacted, several gay men, some with HIV, were scheduled to give evidence. We contacted the Magistrate’s associate to enquire about HALC acting as a ‘friend of the court’ and making an application for suppression. We didn’t yet have contact with any of the witnesses (witnesses in court cases are not ordinarily represented by lawyers), and we had no client with standing before the court to give us instructions. Nonetheless, we were able to make oral representations to Counsel assisting the court regarding the arguments for affording protection to the witnesses’ health information by making suppression orders. To our surprise, those arguments were heeded, and Counsel assisting the court recommended suppression of the HIV status of the witnesses.

As it was, the hearing was inconclusive. No conviction was recorded. No determination about the death or its human causes was made.

Some months later reporting of the case persisted in the local paper. Paucity of material for the local news cycle means that old salacious matters are more likely to be rehashed. In low news periods, review articles detail highlights of local unresolved crime stories – much like campers telling horror stories round a campfire.

We were again contacted by the sexual health nurse asking for help. The main suspect in the court case had had his HIV status, sexuality and life travails exposed in public under the glare of the hearing and the local media interest wasn’t going away. The man was depressed and indicating self-harm. He felt he would have to move from the town where he grew up and where

his family lived. He feared further public humiliation and even harm from other townsfolk.

This man had exhausted his personal and family financial resources on lawyers to represent him at the hearing. He could not afford more legal representation. Legal Aid had refused him assistance previously, since they do not usually assist in matters where there is no risk of custodial sentence. HALC couldn’t assist the man directly due to our previous engagement with the matter. Tactically there would also be a risk that if the man applied for suppression orders himself, it would raise still more adverse media attention if the application failed.

We were in discussion with Positive Life NSW about this matter. They, too, were getting reports of the distress, anxiety and fear raised by the media attention to the HIV aspects of the story. Positive Life instructed us to seek suppression of the names and/or HIV status of the parties to the hearing, even at this late stage, to afford some protection to them and the local HIV-positive population. As the case had concluded, but without determination, it seemed there was scope for such orders. The principle of ‘open justice’ had been served. If any benefit was to arise from the public airing of the material would have occurred by now. Only the sensational and pejorative content of the material was now playing out in the public arena; there was no justice interest in that.

An application was made to the court. In such proceedings the issue of suppression is purely a question of public interest. In practice, the balance is of the principle of open justice against that of the public interest, relevantly, in the administration of justice (would it deter witnesses coming forward), or safety of the public or a person.

We believed we had a good case to make. We provided evidence from the sexual health nurse of the stress and anxiety expressed by HIV-positive clients pursuant to the media interest on the hearing. She spoke of the fear they held of their own status being disclosed and

In a small town, that kind of court hearing would raise considerable local interest anyway, but with the local gay community and HIV infection thrown into the mix the interest was amplified.

similarly publicly reported, and of the potential stigma and discrimination flowing from such disclosure. We also provided evidence from Positive Life indicating the stigmatising nature of the media reporting; highlighting the link between HIV stigma and health outcomes in terms of testing, treatment and transmission-preventive behaviours; underscoring that people with HIV living in regional areas are often more isolated and have fewer supports, noting the greater impact of such stigma and negative publicity on them; and emphasising the public health interest in reducing stigma and combatting it where it arises.

Further to this evidence, we believed the context of the case favoured suppression. The hearing had concluded some months earlier. There was no finding against the main suspect. There was no particular evidence or finding that the HIV content of the story was essential or relevant to the death. The court had already given weight to concerns of other witnesses by giving suppression orders for their status. The court presumably considered the threat to individuals or the public in that consideration. The ongoing reporting was purely salacious with a derogatory slant and not substantive to the matter. The court itself noted that the case was unlikely to be enlivened, though it was not formally closed as no finding had been made. The local Health Department officers were raising the concerns about the local impact for their HIV-positive clients. We saw a strong case where the public interest in open justice was exhausted.

Despite all this, the Magistrate dismissed the application. Finally, the court determined that the public interest in having the names and evidence at large in the public domain outweighed the damage it might cause to individuals or HIV-positive people in the community.

The decision was all round a reaffirmation of the most extreme view of open justice. It was a rebuttal to the notion that public health or specific community concerns might effectively moderate the scope of that principle.

In the shadow of these proceedings, Area Health had contacted other organisations to achieve a remedy. The Australian Federation of AIDS Organisations (AFAO) had previously engaged with media in South Australia with some success when an HIV endangerment case was attracting attention. AFAO's media kit³ and persuasive arguments had modified the media's treatment of that case toward more sober, balanced reporting. AFAO and ACON now engaged in the issue, contacting the media outlet directly and attempting the same persuasive engagement with them.

Some months down the track, we believe the persuasion has worked. Most recent media reporting of the NSW case has significantly toned down the salacious aspects of the case, and shown more balance and maturity in its treatment. It was always hoped that time would quieten interest in the case. Indeed, this was one reason the court gave for not intervening with suppression orders. However, the intervention by AFAO and ACON has given more confidence that regard for the social impact of the reporting will also work to stifle further stigmatising reporting.

Conclusion

The case highlights the vulnerability of HIV-positive people when they are before the courts. Those vulnerabilities are amplified in regional locations where local news content is at a premium. Unlike Victoria, NSW legislation provides no general protections for the HIV-positive community from the flow of such stigmatising content from court

hearings. So strong is the principle of open justice in NSW that lawyers are unlikely to even advert to the possibility of court suppression of sensitive HIV status information.

With any intervention on reporting news, there is fear of a backlash reaction. The fear is that the failure of the intervention will meet with a reaction of heightened interest mixed with righteous cries for media freedom and denunciation of so-called attempts to muzzle the free press. Fortunately, the efforts of AFAO to engender a more mature and responsible media stance have proven successful, as currently in such cases in NSW we have no other defences in our arsenal.

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Iain Stewart Brady is a solicitor at the HIV/AIDS Legal Centre (NSW).

The case highlights the vulnerability of HIV-positive people when they are before the courts. Those vulnerabilities are amplified in regional locations where local news content is at a premium.



Infiltrating the mainstream: the Queensland experience

By **Chris Howard** and **Karen Porter**

'I needed some dental work done and decided to go to my local dentist, instead of the one 100km away from the small town I live in. I completed the form that asked me about medical conditions, including whether I was HIV-positive. When I handed the form over I asked the receptionist what their policies for privacy and confidentiality were, with the added warning my form contained information that was very 'private and confidential'. The receptionist assured me such policies existed and were adhered to. I felt somewhat confident in the protection this afforded me. That the receptionist was also my neighbour however was not reassuring. It struck fear in me.'

In the current climate of fiscal conservatism, it is possible to foresee HIV-specific service delivery in Queensland impacted by reduced public health spending and retracted human and financial resources. It is timely,

therefore, to examine 'mainstreaming' HIV service delivery in light of the factors likely to influence successful mainstream service engagement, at different social-ecological levels of the health care system. An increase in referrals to mainstream services in Queensland may call for a new focus on 'mainstreaming' HIV.

Positive Directions, a program of Anglicare Southern Queensland, was formed in October 2004. At that time, Queensland was the only state in Australia that opted for such a model of care for individuals living with HIV and since then Positive Directions has remained the only organisation of its type in Australia.¹ Our model is a collaborative, coordinated and integrated approach to service provision, providing a suite of holistic supports including self-management education; referral to other services; and care coordination services.

The nature of the HIV epidemic is changing: people are living longer with HIV due to increasingly effective combination antiretroviral therapies. As the epidemic evolves, so do the clinical and social support needs of people living with HIV. As a result, the focus of care for many has shifted to managing co-morbid conditions associated with long-term HIV infection, such as stroke, cardiovascular disease, kidney and liver diseases.²

The current model for the delivery of HIV treatment is based on accessing s100 prescribers for combination antiretroviral therapy: GPs in the community; HIV specialists; and doctors at sexual health clinics.³ While complicated clinical care is best provided by specialist and experienced HIV clinicians, traditional health care that builds largely on acute, episodic models of care is ill-equipped to meet the long-term and fluctuating needs of those with chronic conditions.

Positive Directions is tasked to develop care coordination responses to facilitate access to a range of services that are appropriate to the complex health and welfare needs of people living with HIV throughout Queensland. For people living with HIV, stigma and discrimination and the fear of public exposure and vilification can undermine willingness to engage with mainstream services.⁴ The protection that private and confidential HIV-specific services afford HIV-positive people is highly valued by those who are particularly fearful of and vulnerable to social alienation, including those living in regional, rural and remote communities.⁵

In recent years researchers have examined changes in the location of the HIV-positive population in Queensland, warning of the implications for service delivery and development. Their findings suggest that while differences in service use appear to be related to geographic accessibility of different service types, there may be other important social, economic and cultural factors, such as ageing and socio-economic pressures involved.⁶ Chronic conditions require complex models of care, involving collaboration among practitioners, professions and institutions that have traditionally worked independently of each other.⁷ Positive Directions responded to this need through the development of an integrated, more coordinated approach to service delivery.

Positive Directions constructed a service model that aims to achieve continuity of care and better health and wellbeing outcomes for our clients. This approach seeks to ensure that support and education is delivered to the community and practitioners in a logical, connected and timely manner.

Self-management education focuses on the skills, knowledge, self-efficacy, motivation, resources and information required for an individual to self-determine and actively work towards and achieve health and wellbeing goals.⁸ This core component of our service delivery model works to provide people living with HIV information

that will assist them to self-manage their chronic condition and adopt health and wellbeing enhancing behaviours. To this end, we are skilling staff to deliver a range of Chronic Condition Care Models including the Health Change Australia's Model of Change, the Stanford Model (HIV Adaption), and Brief Interventions for Chronic Conditions (an initiative of Anglicare Southern Qld) – complementary models suited to different service delivery and cultural contexts (i.e. individual/group; clinical/psychosocial support).

Positive Directions has begun work to implement this self-management programming model across Queensland. Under the model, a Coordinated Activity Plan is developed in response to the identified needs of each individual, ensuring engagement is structured towards developing skills, knowledge, self-efficacy and motivation. The goal is to empower and prepare individuals to manage their health and health care.

On interpersonal and organisational levels, the interdisciplinary members of Positive Directions work to provide information to relevant mainstream agencies/service providers on HIV issues and service provision, ensuring such information will enhance sensitivity and understanding.

In 2002, UNAIDS declared 'mainstreaming' an essential approach for expanding multi-sectoral responses to HIV/AIDS.⁹ Mainstreaming is not an end in itself, but a means to ensuring

that HIV is central to all programmatic activities – policy development, research, advocacy, resource allocation, and planning, implementation and monitoring of programs and projects.¹⁰ The objective is to stimulate all entities within the health system to take HIV into account in program development and delivery.

Appropriate HIV mainstreaming is required in key Queensland sectors, particularly education, employment and aged care to engage more people, practitioners, program developers and policy makers. Mainstreaming requires appropriate human and financial resources and there must be commitment to developing partnerships among the various sectors.

In 2010, researchers from the Australian Research Centre in Sex, Health and Society, called for a balance to be struck between mainstreaming HIV service delivery and increasing the accessibility of HIV-specific services.¹¹ To achieve this balance, a proportion of service delivery must transfer to mainstream providers, and this successful transition requires an increased focus on 'mainstreaming' HIV. Mainstreaming cannot develop of its own accord. Systemic advocacy, widespread sensitisation and individual capacity building must occur in order to place people in a better position to undertake 'mainstreaming'.

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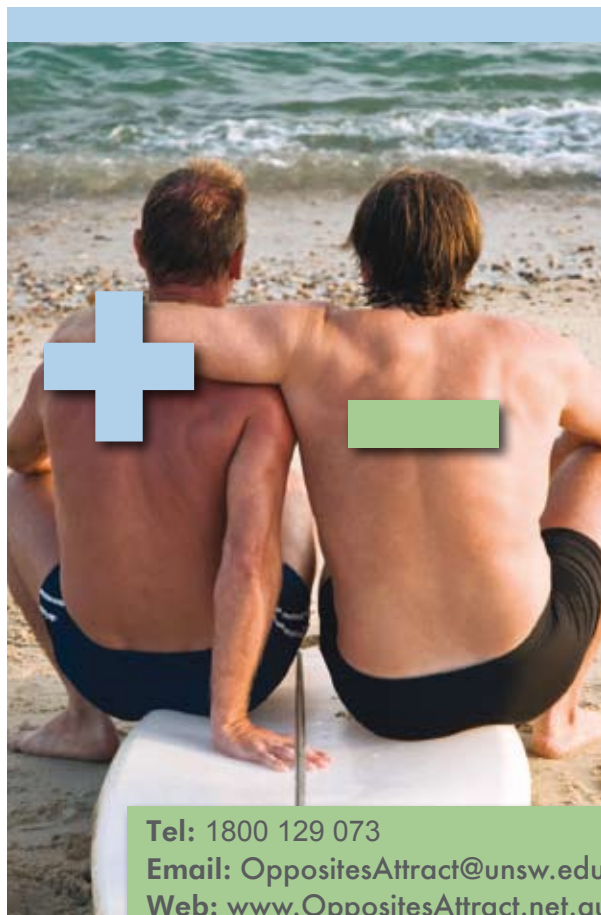
Mainstreaming cannot develop of its own accord. Systemic advocacy, widespread sensitisation and individual capacity building must occur in order to place people in a better position to undertake 'mainstreaming'.

Mainstreaming highlights the importance of broadening and strengthening strategic collaborative partnerships between government sectors, community and health service providers and professional practitioners at all social ecological levels of the system.¹² Mainstreaming efforts of Positive Directions will mean that mainstream services in Queensland are better positioned to respond to the needs of people ageing with HIV who may be experiencing chronic co-morbid conditions that require complex levels of care and support.

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Unjust Treatment: Trans-Pacific Partnership Agreement (TPPA)

By Michael Frommer

During the AIDS 2012 conference in Washington, there was much excitement generated around the prospect of achieving an 'AIDS free generation'; the topic was a major focus of many presentations delivered at the conference.

In the context of recent scientific findings which highlight the effectiveness of HIV treatments as a form of prevention¹, speaker after speaker (including US Secretary of State Hillary Clinton) hailed this moment as a window of opportunity to bring about significant increases in the number of people on treatment globally, to achieve a corresponding decrease the rate of HIV transmissions world-wide.

Despite this optimism, there is a serious tension in the geopolitical landscape around this issue. Governments publically affirm the importance of reducing HIV transmission through, among other things, treating more people sooner after seroconversion, yet negotiations behind closed doors continue on a trade agreement, which – if it proceeds as planned – will severely restrict access to antiretroviral treatments for those who most need them, particularly in developing countries.

TPPA overview

AFAO has grave concerns about the Trans Pacific Partnership Agreement (TPPA)², a proposed new regional trade agreement building on an existing agreement between Brunei Darussalam, Chile, New Zealand and Singapore³. Official negotiations around the proposed agreement commenced in Melbourne on 15 March 2010, and currently involve Australia, Canada, Malaysia, Mexico, Peru, and the USA, with Japan and several other countries having expressed interest in joining in the near future.⁴

AFAO is concerned at the prospect of the TPPA limiting access to HIV medications, as well as other

pharmaceuticals and essential diagnostic services. In fact, access needs to be enhanced for people with a range of significant health conditions – not only for people with HIV, but also for people with cancer and other non-communicable diseases.

A leaked version of the agreement indicates that the United States is seeking expanded intellectual property protections for pharmaceutical products. These increased protections would severely delay and restrict access to affordable medicines by, among other measures, extending patent rights which would lead to delays in cheaper generic drugs becoming available.

According to Dr Deborah Gleeson, a Research Fellow in the School of Public Health and Human Biosciences at La Trobe University, the TPPA will not affect Australia directly due to the Australian Government's position that it will not accept provisions in the TPPA that affect the integrity of the Pharmaceutical Benefits Scheme (PBS).⁵ Nevertheless, the TPPA remains a serious threat to people living with and affected by HIV within our region, and internationally throughout developing countries.

In Asia and the Pacific, only 39% of people in need of treatment have access.⁶

Under the *United Nations 2011 Political Declaration on HIV/AIDS* (the UNPD), all member countries have committed to bold actions and targets including improving access to medications, from 30% of people living with HIV in 2011 to 50% by 2015, as well as reducing the sexual transmission of HIV by 50% by 2015.⁷

These laudable targets cannot be realised if access to treatments are restricted, as would occur under the proposed TPPA. Any additional restrictions on HIV treatments access would not only be a public health disaster but a human rights travesty, seeing corporate profits prioritised over individual and community wellbeing.

Key problems with TPPA

According to leaked versions of the TPPA, the US position would make signatories agree to limit the purchase and use of generics in their countries through mechanisms known as 'TRIPS-Plus' provisions.⁸ Provisions sought by the US include:

■ Broadening the scope of patentability

This would allow for expanded patent protections, by limiting governments' ability to set standards that would define whether a product would be eligible for patent. Governments would be required to grant patents where there are minor alterations to existing drugs. If permitted/implemented, this would increase the cost of production of new drugs.

Currently, national governments are able to define key terms such as 'novelty,' 'inventive step,' and 'industrial applicability' according to the needs and particularities of their country.⁹ This allows for production of generic versions of important medications and means that generic copies – such as Novartis' anti-cancer drug imatinib mesylate (see box on the following page) – are available at a tenth of the price of the original brand.

■ Requesting patent term extensions

Under the current intellectual property legal regime based on the TRIPS agreement, patents must last 20 years. Under the US proposal, the drug companies would be able to extend this period by at least five years to compensate for any delays in the administrative/regulatory/patent processes.

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■ Restrictions on pre-grant opposition

Under this proposal, third parties would be unable to oppose a patent application until the patent has been granted. This is problematic as it allows frivolous patents to be lodged, without patent offices being able to hear views from civil society and others organisations that might challenge the case for patent. Currently, a patent application can be challenged prior to granting the patent.

■ Greater rights for pharmaceutical companies in court

According to leaked versions of the TPPA, provisions would allow companies to sue governments if the regulatory environment negatively affects a company's investments.

The impact of these and other provisions would be to shrink generic competition, leading to higher drug prices.

Hurdles to treatment access

The Global Fund to Fight AIDS, Tuberculosis and Malaria has been key to the international response to HIV. By the end of 2010, more than 5 million people in low and middle-income countries had access to HIV antiretroviral therapy, three million of whom were receiving access through Global Fund-financed programs. Currently, the Global Fund is facing decreasing contributions from donor countries. The Global Fund, along with other HIV funders, including the US President's Emergency Plan for AIDS Relief (PEPFAR), the United Nations Children's Fund (UNICEF), and UNITAID¹² rely on there being structural and policy supports to allow ready supply of and equitable access to good quality generic drugs for those who need them.

With the increased treatment targets under the UNPD, the coincidental decrease in donor funds at a time of more limited access to generic HIV

Case study: Novartis v Indian Patent Office

Novartis, a Swiss drug company, is currently challenging the Indian Patent Office's 2006 decision to reject the drug company's application to broaden the scope of their original patent for the anti-cancer drug imatinib mesylate.¹⁰ The grounds for rejection were that the application was for a 'new form of a *known* (emphasis added) substance.' The Patent Office's rejection of Novartis' application would not be possible if, as leaked versions of the TPPA indicate, the scope of patentability is broadened.

Case Study: Phillip Morris v Australian government

While the tobacco company Phillip Morris recently lost its High Court challenge of the Government's plain packaging legislation, they are still disputing the legislation under Australia's bilateral investment treaty with Hong Kong. According to ANU Law Professor, Don Rothwell, the key aspect of Philip Morris' claims against the Australian government is that the proposed plain packaging law results in unreasonable measures that impair the enjoyment of an investment. Investment is broadly defined under the treaty to include intellectual property.¹¹

treatments will inevitably lead to many of those most in need of affordable antiretrovirals to miss out. But the lack of funding is not the sole issue hindering the global response to HIV – as politicians in the EU and US may argue. Rather, it is a lack of political will to ensure equitable access to HIV medications.

Governments are responsible for ensuring that all citizens, including people with HIV, can access affordable life-saving and enhancing treatments. This obligation must trump the commercial interests of powerful and profit hungry pharmaceutical/corporate lobbies.

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Towards the finish line? Trial of needle syringe and program announced for ACT prison

By Finn O'Keefe¹

After many years of advocacy from health and community organisations, the much anticipated trial of a needle and syringe program (NSP) for ACT's prison, the Alexander Maconochie Centre (AMC), has been given official approval from the ACT government to go ahead. The program will be the first of its kind in Australia, as a strategy to reduce the transmission of hepatitis C and other blood borne viruses (BBV) within the AMC prison.

The government's announcement regarding this politically controversial issue came as something of a surprise. It was made by ACT Chief Minister, Katy Gallagher, during a Justice Health Symposium hosted by the Public Health Association (PHAA) in Canberra, on the morning of 15 August. The announcement was met with a standing ovation.

In her speech, the Chief Minister stated that the implementation of the draft *Strategic Framework for the Management of Blood-Borne Viruses in the Alexander Maconochie Centre 2012–2014* would involve further 'targeted consultation' as part of finalising the framework and the implementation of the equipment exchange program.

The announcement was welcomed by health and community advocates, including the Australian Injecting and Illicit Drug Users League (AIVL),

NSW Users and AIDS Association (NUAA), Canberra Alliance for Harm Minimisation and Advocacy (CAHMA), the Australian Medical Association (AMA) and the PHAA. Nicole Wiggins, CAHMA Manager, described the announcement as 'an important symbolic moment', saying that 'the ACT Government has shown rare political leadership and has openly acknowledged their statutory responsibility for the health and wellbeing of prisoners in the ACT'.

However, a number of significant concerns remain. The first of these is that the consultation process could further delay the program's commencement, as Nicky Bath from NUAA explains:

'We support the ACT Government's approach of including the equipment exchange program as part of a broad based BBV management strategy of prevention, testing, treatment and support. In taking a comprehensive approach to addressing BBVs in the AMC, it is very important however, that the planned 'targeted consultation' process does not delay or impede the implementation of the equipment exchange program. There will need to be cooperation across all key stakeholders to ensure access to new injecting equipment in the ACT prison becomes a reality as soon as possible because injecting equipment is being reused

repeatedly as we speak. In this regard, we hope other states and territories now follow the ACT's lead and implement NSP in prisons across Australia.'

Australian research evidence reflects the enormous contribution that access to new injecting equipment has had in the general community in relation to preventing HIV and hepatitis C. Internationally, NSPs have also been successfully tried or implemented in 50 prisons internationally², with the first of these programs being introduced in Switzerland in 1992³. Considering this, the trial of a needle syringe program in an Australian prison setting seems extremely overdue and the continued lack of any such program presents a formidable barrier to BBV prevention in this context. In the ACT alone, it is estimated that up to 65% of prisoners in the AMC have hepatitis C. This includes nine prisoners who have contracted hepatitis C within the AMC since it opened.

Despite a prison-based NSP trial being evidenced-based policy which is endorsed by the Australian HIV, hepatitis C and the Aboriginal and Torres Strait Islander Blood Borne Viruses and Sexually Transmissible Infections strategies agreed to by all State and Territory Health Ministers,

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the proposed NSP trial for the AMC is still perceived as controversial. Over the last few years, the proposed trial has met with continued resistance from the Community and Public Sector Union (CPSU), the union representing Australian prison corrections officers, even after the former ACT Chief Minister, Jon Stanhope, stated in 2010 that he had changed his mind on the issue and would be more likely to accept such a scheme.⁴

The ACT Regional Director of the CPSU, Vince McDevitt, has declared that his members are ‘unanimously’ opposed to any NSP prison trial, citing safety concerns⁵. The Health Services Commissioner at the ACT Human Rights Commission resigned from the CPSU in September 2011 over the CPSU’s position against NSPs⁶.

The NSP model for the AMC that has been given government approval is ‘one-for-one’, meaning the prisoner only receives clean injecting equipment in exchange for used equipment, under the supervision of medical staff.⁷ A spokesperson for AMA has said he believes that the one-for-one model will be more widely accepted⁸, but it is not yet clear whether this will be enough to allay the concerns of those seeking to block the establishment of an NSP trial at the AMC.

Following the announcement of the trial, Vince McDevitt said: ‘We welcome of course any sort of involvement by medical professionals such as doctors but we need to see the detail.’⁹ Although it is hoped other States and Territories will follow the ACT’s lead, South Australia’s Department of Correctional Services has already stated that it will not support such a program under its jurisdiction because it fears that syringes would be used as weapons.¹⁰

AIVL sees a number of other concerns relating to the proposed model of one-for-one needle exchange at the AMC prison. As Jude Byrne, Senior Project Officer at AIVL, explains:

‘One-for-one needle exchange is hardly easy access. What happens to all the

people sharing that one syringe? That [practice] continues, obviously. Having to make an appointment to make the exchange is not only not confidential, it’s incriminating.’

These issues are just some of the problems Jude Byrne sees with the NSP model that has been proposed. She also says that the proposed scheme is in direct conflict with the UN International Labour Organisation (ILO) guidelines that state ‘prisoners who inject drugs should have easy and confidential access to sterile drug injecting syringes and paraphernalia and should receive information about the programmes.’¹¹

Annie Madden, AIVL Executive Officer, says it is critical that we implement the correct model: ‘We need to recognise the real, human impact that NSPs have. Quite simply, NSPs save lives. To this end, it is critical that when we implement NSP in the prison context, we need to get it right.

‘What we know from NSPs in prisons overseas is that how programs are implemented and the way they are delivered is critical and can make the difference between an effective and ineffective outcome. Prisoners are a highly marginalised population and we have a responsibility as a community to ensure their health and human rights are protected. As the ACT Government moves forward on this ground-breaking initiative, representatives of people who inject drugs will be willing partners in making sure this new program is given every chance to be effective and in doing so, save lives,’ Annie Madden concludes.

It is anticipated that the first trial of an NSP within an Australian prison could commence as soon as 2013, however this is subject to the timetable of the consultation process. Although there are still a number of significant hurdles to overcome, hopefully the finish line will soon be in sight.

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Regional Feature: The GWL-INA: the formation of a national network of gay men, transgender and MSM in Indonesia

By Salina Abigail

Introduction

In October 2005, the Australian Federation of AIDS Organisations (AFAO) funded a needs assessment for gay men, men who have sex with men (MSM) and *waria* (transgender)¹ communities in Indonesia. The study found that these communities were extremely marginalised and were at high risk of acquiring HIV and other sexually transmissible infections (STIs).² The study also indicated that less than 10% of the total estimated number of openly or identifiable gay men, MSM or *waria* community members had access to HIV and STI prevention and care and support services.³

In response to these findings, in 2007 a group of gay men, MSM and *waria* came together to establish a network of community organisations to help foster an enabling environment to support

the scale-up of HIV prevention and care programs for gay men, MSM and *waria* communities in Indonesia.

The GWL-INA⁴ network is an advocate and coordinating body that helps strengthen the capacity of community organisations to ensure that the issues and needs of gay men, MSM and *waria* in Indonesia are reflected in the development and implementation of domestic HIV and AIDS related programs and policies.

Today, GWL-INA is a national network with 68 community-based organisations in 25 provinces listed as members. Any gay, MSM or *waria* organisation or group that implements HIV/AIDS programs in Indonesia is able to join, and members are not required to pay any membership fees or sign any agreements or contracts.

Pictured: GWL-INA Members, Board Members, National Secretariat at the network's National Meeting in February 2012

This article provides snapshot of the history of GWL-INA since its inception. The text is drawn primarily from a report developed by GWL-INA and Salina Abigail, an Indonesian consultant, with support from AFAO and the Alliance Technical Support Hub for South East Asia and the Pacific. The full report (in English and Indonesian) *The GWL-INA: The Story of A Network* is available online at www.afao.org.au Printed copies of the report will also be distributed to other nascent networks throughout Indonesia and the Asia region.

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Giving communities a voice

Indonesia is home to over 17,000 islands and over 200 million people.⁵ It is the fourth most populous country in the world⁶ and one of the most culturally diverse, with a great variety of local cultures and hundreds of local languages and dialects.

Although Indonesia has a history of tolerance towards homosexuality, in recent years the rise of fundamental religious groups has contributed to an increase in homophobia and violent actions against gay men, MSM and *waria* communities.

Many gay and *waria* activists report that daily raids and physical abuse of gay men, MSM and *waria* is a common occurrence. Gay, MSM and *waria* groups and organisations – especially in small cities – regularly receive threatening letters. Reporting to the police has proven to be useless, as the police only request payment for their protection.⁷

Living in such a conservative community, gay men, women and *waria* in Indonesia are subjected to constant humiliation and abuse. It is difficult for gay men to ‘come out’ to their families and they often lead a double life – being married to a woman while secretly having sex with other men – to avoid being shunned by their families and community.

The establishment of the GWL-INA network is considered a key event in the national gay, MSM and *waria* movement. When the GWL-INA was first established, very little programming existed specifically for gay men, MSM and *waria*. Now, for the first time ever, these groups have a voice in the coordination of Indonesia’s national HIV response.

As a member of the National AIDS Commission (NAC), the network has gained the respect and attention of the Indonesian government and has developed a *National Strategic Action Plan* that complements the existing *2010–2014 AIDS National Strategy and Action Plan*, providing clear guidance for the development and implementation of HIV and AIDS response programs targeting gay, MSM and *waria*. With other civil society groups, the network has also launched a joint advocacy campaign on the rights of people living with HIV (PLHIV).

HIV surveillance data

HIV in Indonesia continues to spread at an alarming rate, with men who have sex with men being disproportionately affected. Many of these men do not have adequate access to information on HIV because, historically, the government has not been very active in distributing information to these communities.

The most recent *Integrated Biological-Behavioural Surveillance (IBBS) 2011*, carried out by the Ministry of Health, identified that HIV prevalence among MSM in Indonesia has almost tripled over the last four years – rising from 5.3 % in 2007 to 12.4% in 2011.⁸ There has been a slight decrease in HIV prevalence among *waria*, from 24.3% in 2007 to 23.2% in 2011. For both MSM and *waria*, however, there has been an increase in rates of syphilis (from 4% to 13% for MSM and 27% to 28% for *waria*).⁹

Despite these challenges, improvements have been made. Compared to findings from IBBS 2007, the IBBS 2011 found increased condom use among MSM and *waria*, from 28% to 32% (MSM) and 37% to 41% (*waria*).¹⁰

Funding for HIV and AIDS programs targeting gay, MSM and *waria* has also increased. However, the majority of funding still comes from foreign donors. The GWL-INA network has helped empower gay, MSM and *waria* organisations to build a strong foundation which has enabled them to secure sustainable funding from other sources, including AusAID, the Global Fund to fight AIDS, tuberculosis and malaria.

Network activities

The GWL-INA was declared a network on 4 February 2007. Initially, membership of the network consisted only of an e-group. Four key people (Dede Oetomo, Tono Permana, Sarjono Sigit, and Poedjiati Tan) maintained the momentum by moderating the online discussions. Tono and Dede were particularly instrumental in mobilising the resources needed for the network to grow.

In October 2009, the GWL-INA held its first National Meeting, where Tono Permana Muhammad was elected as the network’s first national coordinator.

At the time of the network’s establishment, very little programming existed specifically for gay men, MSM and *waria*. Not enough resources were allocated for these population groups.

Although Indonesia has a history of tolerance towards homosexuality, in recent years the rise of fundamental religious groups has contributed to an increase in homophobia and violent actions against gay men, MSM and *waria* communities.

In the five years since its establishment, the GWL-INA has been working very hard to reverse this situation.

GWL-INA's activities have focused heavily on building the internal capacity of the network, and improving the outcomes of HIV program implementation for gay men, MSM and *waria*. The network developed the *National Strategy and Action Plan for Gay, Waria, and MSM 2010–2014*, which complements the *2010–2014 AIDS National Strategy and Action Plan* and provides clear guidance for policy makers and stakeholders in developing and implementing HIV and AIDS response programs for gay, MSM and *waria* groups. Tono Permana Muhamad presented the action plan in the first plenary session at the 10th International Congress on AIDS in Asia and the Pacific (ICAAP10) in Busan, South Korea.

The GWL-INA formally became a member of the National AIDS Commission (NAC) in February 2012. This is a huge achievement for a country as conservative as Indonesia, as it means that, for the first time gay, *waria* and MSM populations are recognised nationally and sit in equal positions as ministries and government agencies. As a member of NAC, the GWL-INA network participates in consultation and coordination meetings on the national HIV response.

The increase in HIV prevalence among men who have sex with men, as found in the recent IBBS, has prompted the network to put an even greater emphasis on HIV prevention programs for gay, *waria* and MSM. An example of this is the 'GWL-Muda' (Young GWL) group, established in January 2012 to target young gay, *waria* and MSM. The group developed 'brondong manis', a web-based information centre designed to equip young gay, *waria*, and MSM with adequate information on sexual and reproductive health and rights, assertive communication and negotiation, drugs, and linkages to health services. The website (www.brondongmanis.com) also serves as a dating portal for young gay men, MSM and *waria*.

The GWL-INA network also carries out advocacy campaigns with other civil society groups. One example is 'ODHA berhak sehat' (www.odhaberhaksehat.org), campaign about HIV-positive people's rights to health, jointly undertaken with Indonesia AIDS Coalition (IAC) and the national network of women living with HIV (IPPI).

This campaign provides a virtual discussion room, a safe space for people with HIV to discuss a broad range of issues, including general discussions, new information about treatments, access to treatment and advocacy to improve treatment access.

The GWL-INA network also joined 'Aliansi Satu Visi' (One Vision Alliance) and the Lesbian/ Gay/ Bisexual/ Transgender/ Intersex/ Queer (LGBTIQ) Forum in advocating and raising awareness on sexual diversity.

In October 2011, GWL-INA became one of four sub-recipients of the Global Fund Round 10 ISEAN-HIVOS¹¹ multi-country grant. The grant is intended to address critical gaps in supporting and scaling up activities that reduce HIV/ AIDS among MSM and transgender people. Activities and service delivery areas outlined in the grant are aimed at building the capacity of the community to engage with the government to increase the scope and effectiveness of service delivery, develop

appropriate policies, and create an enabling environment to address stigma and discrimination.

Achievements and challenges

Perhaps the biggest achievement for the GWL-INA is that it has united the voices of gay, *waria* and MSM communities in Indonesia. The network maintains this unity by not tolerating stigma and discrimination within the network. In this sense, the GWL-INA has truly become a family for its members.

The GWL-INA has succeeded in gaining the respect and attention of government agencies – the NAC in particular – to gay, *waria* and MSM issues, ensuring that the issues are represented in national HIV response coordination meetings.

Funding availability for programs targeting gay, *waria* and MSM has increased significantly since the network was established. The Round 10 Global Fund multi-country ISEAN-HIVOS grant provides additional resources needed to improve coverage of programs targeting gay, MSM and *waria* in the implementation of the *HIV and AIDS National Strategy and Action Plan 2010–2014*. The grant will

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The GWL-INA formally became a member of the National AIDS Commission (NAC) in February 2012. This is a huge achievement for a country as conservative as Indonesia, as it means that, for the first time gay, *waria* and MSM populations are recognised nationally and sit in equal positions as ministries and government agencies.

also strengthen the gay, MSM and *waria* communities' representation in policy making as well as in supporting the development and delivery of national HIV and AIDS prevention campaigns. The grant allows the network more independence by becoming less 'donor-driven', as well as strengthening its position in the national HIV and AIDS political landscape.

Although the national coordinator, Tono Permana Muhamad, says that increased funding can result in more pressure, he says that it provides the network with much-needed assistance to improve its performance as a national network. As a result of increased funding, some network members feel that overall program management for gay, *waria* and MSM groups has become more focused, and that the network provides easier access for funding allocations.

Despite the funding increase, most gay, *waria* and MSM organisations still have low financial management capacity. Many programs are still project based, which means that sustainability remains a major issue. Due to limited capacity, it is difficult for these organisations to lobby the government (at the province/district level) for increased budget allocation for gay, *waria* and MSM programs. One of the network's

strategies to address this is through mentoring and peer support training (network members providing capacity building training program for each other).

The road ahead

The GWL-INA realises that its journey as a network is only beginning. Despite many achievements, there are still many issues to be addressed.

Major improvements are still needed for HIV prevention efforts targeting gay men, MSM and *waria*, as HIV infection rates throughout Indonesia continue to increase. At the same time homophobia and transphobia still exist, resulting in the continued harassment and abuse of gay men, MSM and *waria* across the country.

While capacity building remains an important area of the network's action plan, more focus will be given to scaling up HIV prevention and human rights advocacy campaigns. These are just a few of the strategies that the network has identified in its new strategic action plan for 2012–2015.

The road ahead is very long for the GWL-INA. One day, the network hopes to see sexual diversity acknowledged and respected in Indonesia, with no further HIV infection among gay men, MSM and

waria. This is the big dream for which the network will continue to fight.

The GWL-INA will continue being the voice of its constituents, building the capacity of the communities and advocating for their rights. As a senior MSM activist in Indonesia said, 'You cannot stop the ground from swelling. You cannot hold back the power of the community.' For the GWL-INA, the ground is just beginning to swell.

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Salina Abigail is a Bangkok-based consultant, specialising in developing documentation and proposal writing. She was involved in developing GFATM Round 9 AIDS proposal for Indonesia together with the Indonesian National AIDS Commission and in the development of Round 10 multi-country proposal led by Asia Pacific Network of PLHIV (APN+). Salina has a strong background in developing and managing programs for female drug users.

Major improvements are still needed for HIV prevention efforts targeting gay men, MSM and *waria*, as HIV infection rates throughout Indonesia continue to increase. At the same time homophobia and transphobia still exist, resulting in the continued harassment and abuse of gay men, MSM and *waria* across the country.



**BOOK REVIEW:
MOVEMENT, KNOWLEDGE,
EMOTION: GAY ACTIVISM AND
HIV-AIDS IN AUSTRALIA**

By Jennifer Power. Australian
National University (ANU) E Press

Australia's public health response to HIV is often cited as one of the world's most successful. This history of this response is also well-documented, with Neal Blewett, Minister for Health in the Hawke government, usually credited with introducing the innovative approach of involving communities affected by HIV. Harm minimisation and the 'partnership' approach to public health prevented what could have been many more deaths.

In her history of gay activism and HIV, Jennifer Power traces the development of the 'AIDS movement' and its influence on public policy in Australia. Power's book began as a doctoral thesis, and her analysis is clearly grounded in social movement theory and the sociology of emotions. Social movement theory theorises the relationship between collective social action and the state, and there can be few more obvious examples of this than the AIDS movement, which was explicitly aimed at influencing government policy.

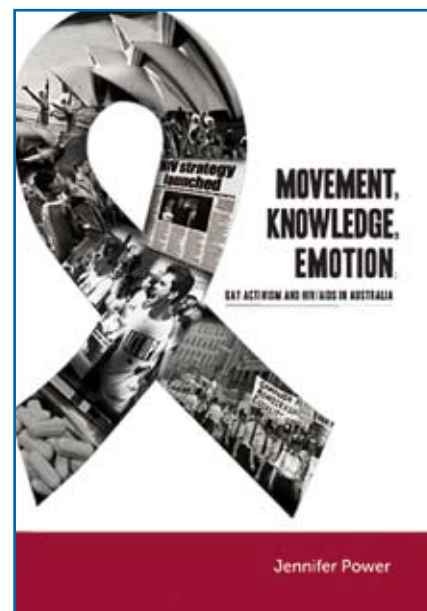
This approach serves Power well, providing a unifying theme to her account of the epidemic through the 80s and early 90s, examining 'how the actions of the movement contributed to changing public knowledge about, and attitudes towards, homosexuality, and how activists were able to inject a new perspective about the role of community into the Australian medical and public health system' (p. 53). This

familiar history becomes surprisingly engaging as Power weaves theoretical insights with contemporary media coverage and reflections from some of the gay men who were involved in the response to HIV. And it is very much about gay men, as it was they who made their response to AIDS into a social movement. Power emphasises the intimate relationship between homophobia and the fear of AIDS and conversely, between gay pride and community action.

The narrative is at its best when it addresses the emotions that drove the gay community's response to HIV. Many of the names that appear in the book will be familiar to those who have worked in the HIV sector in Australia: Bill Bowtell, David Plummer, Dennis Altman, Don Baxter, Bill Whittaker, David Menadue. I found myself involuntarily seeking out their reflections, which sit beside the main text.

Those with more detailed knowledge of the history of the epidemic will no doubt find holes in this account, but it certainly evokes the emotions of the time. It's easy now to forget the level of ignorance and hysteria that surrounded AIDS in the 1980s. One can't help but feel admiration for those gay men who stood up in the midst of so much fear, uncertainty and grief. Their pride and far-sightedness shaped the response to HIV.

Unfortunately *Movement, Knowledge, Emotion* rather trails off as the shape of the Australian response to HIV is solidified in the early 90s. The story of HIV did not end with the quilt project, and there are so many other



questions that the maturing of the AIDS movement gives rise to. What happens to a social movement when it does become a legitimate voice? What problems does that present, and how are those to be addressed? Power provides a cursory analysis of 'bug chasers' and 'gift givers' in the context of the Michael Neal case in Victoria, arguing that media coverage of that case was also imbued with homophobia but that it did not 'have the same 'bite' that it would have had in the 1980s' (p. 417). But what happens when the media – or indeed, government – loses interest in the story? What happens to a social movement then? It may be a sign of the book's strengths, but I found myself left wanting more of this story.

Available in e-book format as free download at: http://epress.anu.edu.au/titles/gay_activism_citation. Also available in hard copy, on request from ANU Publishing.

Harm minimisation and the 'partnership' approach to public health prevented what could have been many more deaths.

Responding to the issues raised by rural PLHIV

Participant discussion at Rural.Life+ has already impacted PLSA activities, and will guide our service provision into the future.

At the workshop itself, it was clear that rural HIV-positive people are often unaware of Adelaide-based services, or simply assume that these will be irrelevant to them. PLSA has invested significant resources into our online presence (website, closed Facebook group for positive gay men, and blog), to try to optimise our connection with members and other rural people living with HIV. The weekend provided a useful opportunity to promote existing services which are genuinely relevant to rural positive people.

A key issue that emerged was access to medical and social services. Participants talked about pressure from medical specialists to move to the city. Whilst no HIV-specific services exist in country areas of SA, participants exchanged resources that they'd found helpful (for example, travel assistance and Medicare-funded chronic disease provisions), and several had found a local GP who was keen to treat them and learn more about HIV.

Few people were aware of Medicare-funded allied health services available to people with chronic diseases through GPs. Immediately following

the workshop, PLSA researched these options and developed a plain English *Info Update* of the available schemes, which increase the likelihood of rural people living with HIV being able to access allied health, mental health and (then available) dental services in their local region, reducing their need to come to Adelaide for non-HIV specific services. We also compiled an *Info Update* on support services, including HIV-interested mental health practitioners in rural areas and phone/online counselling options.

HIV treatment protocols, medical information and peer-based information about the impact of particular treatments are constantly changing. Participants showed particular interest in a number of treatments-related topics. As a result, PLSA wrote and published several articles for our newsletter *Positively Talking*.³

Participants were almost equally divided between those who had disclosed and those who had not disclosed their HIV status to others in their local community. Several recounted positive experiences of 'coming out as positive' in rural settings, and felt that they received higher levels of support than they would in a capital city. At the other extreme, several people felt very isolated. They were very secretive about their HIV status and were sure that coming out locally would

have serious detrimental consequences. All were interested in better understanding the legalities of HIV disclosure. Participant feedback will inform a guide on HIV disclosure and the law in South Australia currently being produced by the HIV/AIDS Legal Centre (HALC).

Into the future, PLSA is committed to addressing community services and health industry workforce issues affecting rural people living with HIV. We aim to improve the cultural competence of HIV services to respond appropriately to positive people living in rural areas and educate GPs about issues affecting HIV-positive patients. (Several rural GPs have inadvertently 'outed' people in their local community through making comments in the waiting room or enabling receptionists to access sensitive information.) Subject to funding, we plan to develop a resource for rural GPs entitled *If you have an HIV+ patient ...*, and provide training for country health professionals.

Finally, within PLSA, we will endeavour to provide earlier notice of 'diary dates'. This will allow rural people living with HIV to align their quarterly medical trips to Adelaide with opportunities to participate in peer-driven events.

For more information contact Suzi Quixley at Positive Life SA, (08) 8293 3700 or healthpromotion1@hivsa.org.au

Endnotes

- 1 Covering all meals, shared apartment accommodation, travel and parking for 20 participants and their partners would cost between \$10,000–\$15,000.
- 2 This cost \$4,000 for a single advertisement published once.
- 3 Available online at: <http://www.hivsa.org.au/pt/pt.html>

At the other extreme, several people felt very isolated. They were very secretive about their HIV status and were sure that coming out locally would have serious detrimental consequences.

Suzi Quixley is Health Promotion Officer at Positive Life SA.



TREATMENT BRIEFS

NEAR-PERFECT ADHERENCE NEEDED TO SUPPRESS CELL-ASSOCIATED HIV

Complete adherence to Antiretroviral therapy (ART) is needed to ensure suppression of cell-associated HIV, investigators from the Netherlands report in the online edition of the *Journal of Infectious Diseases*. A total of 40 people taking long-term HIV therapy were included in the study, all of whom maintained an undetectable viral load. However, modest non-adherence to treatment was associated with increases in cell-associated virus.

'Patients who do not fail on ART, but are even modestly non-adherent, may still have ongoing low-level residual HIV replication,' comment the authors. 'ART only blocks infections of new cells, and not HIV-1 RNA transcription in infected cells.'

They believe their findings could have important clinical implications, and that 'full adherence to modern ART' is required to achieve suppression of cell-associated virus.

Adherence – taking all doses of anti-HIV drugs exactly as prescribed – is central to the success of HIV therapy. Poor adherence can lead to inadequate viral suppression in plasma, the emergence of drug resistance and treatment failure.

The level of adherence needed to achieve and maintain viral suppression with early antiretroviral regimens was 95%. However, more potent drugs with long half-lives have since been developed, meaning that an undetectable plasma viral load can be achieved with much lower levels of adherence, possibly as low as 70%.

It is unclear if HIV replication is completely suppressed when adherence

is less than perfect. Research has focused on changes in plasma viral load. It has not previously addressed the association between adherence and HIV replication in cells.

'We investigated whether residual replication could be promoted by modest non-adherence to ART,' explain the investigators. 'We studied the influence of slightly decreased adherence to therapy on the changes in levels of cell-associated viral markers'. They believe their results 'suggest that constantly optimal adherence to ART may be required life-long'.

The findings could have real clinical significance. Antiretroviral therapy has been associated with significant improvements in prognosis for people with HIV. However, even with such treatment, the life expectancy of HIV-positive people is generally still poorer than that of HIV-negative individuals. The investigators speculate that this could be due to damage caused by residual HIV replication when adherence is less than perfect. 'It is plausible that constant low-level virus replication would exert continuous pressure on the immune system and cause additional morbidity as a result of persistent immune activation, inflammation, and immunosenescence.'

The findings of the study could therefore have implications for advice given to people about adherence. 'Forgiveness of ART, defined as an ability to maintain complete viral suppression despite imperfect adherence, may require re-evaluation in view of our results,' conclude the authors.

Reference

Pasternak, A., et al. (2012). Modest non-adherence to antiretroviral therapy promotes residual HIV-1 replication in the absence of virological rebound in plasma. *J Infect Dis*: online edition.

Michael Carter, *Aidsmap*
Published: 5 September 2012

DOSING FREQUENCY AND NUMBER OF PILLS DON'T AFFECT HIV TREATMENT OUTCOMES

Levels of adherence to modern HIV treatment are unaffected by dosing frequency or number of daily pills,

Italian investigators report in *HIV Medicine*. However, people who were taking larger numbers of pills reported poorer health. The investigators suggest this is because 'many of the patients receiving more complex regimens had more advanced disease and/or were harbouring virus with more drug-resistance mutations'.

It has been uncertain if frequency of dosing and daily pill burden affect adherence to antiretroviral therapy. Research conducted soon after combination HIV treatment was first introduced showed that adherence and outcomes were poorer in people taking more complicated regimens with larger numbers of pills.

There have been significant advances in HIV therapy in recent years, with treatment becoming simpler, more potent and less toxic. Italian investigators wanted to gain a better understanding of the relationship between the number of daily doses and pills and HIV treatment outcomes in the era of modern antiretroviral therapy. They therefore designed a study involving 2114 people who received HIV care in Milan between March and May 2010. Adherence and self-reported health status were assessed using questionnaires.

Adherence levels did not differ according to whether treatment was taken once or twice a day: the study investigators found that people were equally likely to have missed at least one dose of their medication in the previous week (17% vs 16%) and to have stopped treatment for two or more days in the previous month (11% vs 10%).

People with an undetectable viral load reported better adherence than those with a detectable viral load (95% vs 88%, $p < 0.002$). Higher levels of adherence were also associated with better self-rated health status ($p < 0.001$).

'We observed a direct correlation between self-reported health status and adherence, which suggests that patients experiencing more drug side effects

continued overleaf

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not only experience worse health, but are also more likely to miss doses,' comment the investigators.

CD4 cell counts were highest in people who had the best adherence ($p < 0.001$).

Taking a greater number of pills each day was associated with poorer self-rated health status ($p = 0.019$). However, there was no evidence of a relationship between frequency of dosing and health status.

'Better self-reported health status was associated with a lower pill burden,' write the authors. 'Neither the number of daily pills nor dosing interval was associated with self-reported adherence.'

They believe their findings show that 'when a regimen is well tolerated, adherence and health status are very good, regardless of the number of daily pills or the dosing schedule.'

The investigators stress that their study participants were 'highly adherent and virologically suppressed' and conclude: 'self-reported adherence was not associated with the number of daily pills or dosing interval.' They believe their findings 'may be clinically important when, because of toxicity, a patient is a candidate for a switch from a very simple nucleoside reverse transcriptase inhibitor (NRTI)-based regimen to a more complex NRTI-sparing regimen.'

Reference

Gianotti, N., et al. (2012). Number of daily pills, dosing schedule, self-reported adherence and health status in 2010: a large cross-sectional study of HIV-infected patients on antiretroviral therapy. *HIV Med*, online edition. DOI: 10.1111/j.1468-1293.2012.01046.x, 2012.

Michael Carter, *Aidsmap*
Published: 04 October 2012

CNS SYMPTOMS COMMON IN PEOPLE TAKING RALTEGRAVIR

Approximately 10% of patients taking the antiretroviral drug raltegravir (*Isentress*) develop central nervous system (CNS) side-effects, research published in the online edition of *AIDS* shows. The

development of CNS side-effects was associated with the co-administration of tenofovir (*Viread*, also in *Truvada*, *Atripla* and *Eviplera*) and of proton pump inhibitors (drugs used to reduce gastric acid). The investigators believe these drugs interact with raltegravir, increasing its plasma concentrations.

Raltegravir is the only integrase inhibitor so far approved for the treatment of HIV. Clinical trials conducted during the development of raltegravir showed that the drug had a good safety profile. However, some people developed CNS symptoms and there have been case reports of worsening depression and the development of insomnia in people initiating raltegravir therapy.

Italian investigators therefore looked at the prevalence of and risk factors for CNS side-effects in people taking raltegravir in routine HIV care.

Their study sample included 453 raltegravir-treated participants. They were monitored at six-monthly intervals, when they were asked if they had developed CNS symptoms such as headache, dizziness, anxiety, depression and sleep disturbances.

'Our data suggest a possible correlation between high raltegravir plasma concentrations and CNS symptoms,' write the authors.

They recommend 'a careful evaluation of patients with psychiatric disease prior to starting raltegravir and a continuous monitoring of CNS symptoms in clinical practice in those starting the drug'. The authors also stress the need to check for drug interactions than could lead to an increase in raltegravir levels. Therapeutic drug level monitoring could be useful, they suggest, for people experiencing CNS symptoms.

'Further prospective studies are needed to better clarify risk factors, the role of drug-interactions and the clinical significance of CNS symptoms in patients receiving raltegravir,' conclude the researchers.

Reference

Madeddu, G., et al. (2012). Raltegravir central nervous system tolerability in clinical practice: results from a multicenter observational

study. *AIDS* 2012 Oct 1. [Epub ahead of print]. *AIDS* 26, online edition. DOI: 10.1097/QAD.0b013e32835aa141, 2012.

Michael Carter, *Aidsmap*
Published: 10 October 2012

HIV TREATMENT IS NOW FREE IN ENGLAND FOR ALL WHO NEED IT

The removal of charges for undocumented migrants and non-UK citizens accessing HIV treatment and care in England came into effect 1 October 2012. From now on, HIV treatment will be provided free of charge to all who need it, regardless of citizenship or immigration status.

The move was first announced in February and the relevant legislation passed in June. Health ministers have justified the change on the grounds of public health, pointing to the impact that HIV treatment has on onward transmission.

Although it was initially proposed that free HIV treatment should only be available to people who have been living in the UK for more than six months, this requirement has not been retained in the legislation.

While treatment in HIV clinics will always be free of charge, migrants living with HIV who need hospital treatment for another health condition, such as diabetes, heart disease or cancer, or who require antenatal care, may still be subject to charging regulations.

Moreover, the rules have only changed in England. In Scotland and Wales, the legislation still states that HIV treatment may be chargeable, although charges for HIV treatment have not been levied or actively pursued in recent years.

In Northern Ireland, the legislation still states that HIV treatment may be chargeable, and these regulations have sometimes been rigorously enforced.

The National AIDS Trust has called for a formal change in the law in Scotland, Wales and Northern Ireland, to ensure that free universal access to HIV treatment is guaranteed across the UK.

Roger Pebody, *Aidsmap*
Published: 1 October 2012

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● **November**

5–6

3rd International Workshop on HIV and Ageing

Baltimore, United States of America
<http://www.virology-education.com>

8–10

The National Primary Health Care Conference 2012 – Healthy Communities, Healthy Nation

Adelaide, Australia
<http://www.amlalliance.com.au/events/national-conference/registration>

11–14

LEPH 2012 – 1st International conference on law enforcement and public health

Melbourne, Australia
<http://www.policing-and-public-health.com>

11–15

Eleventh International Congress on Drug Therapy in HIV Infection

Glasgow, United Kingdom
<http://www.hiv11.com>

20–21

First National Sexual and Reproductive Health Conference

Melbourne, Australia
<http://www.shfpa.org.au/images/shfpapahaconf2012.pdf>

● **December**

3

6th International Workshop on HIV Persistence, Reservoirs and Eradication Strategies

Miami, United States of America
<http://www.hiv-workshop.com/workshop-2013.htm>

4–7

HIV DART 2012: Frontiers in Drug Development for Antiretroviral Therapies

San Diego, United States of America
<http://www.informedhorizons.com/hivdart2012/>

2013

● **January**

14–15

3rd International Workshop on HIV and Women

Toronto, Canada
<http://www.virology-education.com>

● **February**

1

1st Discourse and Narrative Symposium: Stigma and Exclusion in (Cross-) Cultural Contexts

Brisbane, Australia
<http://www.slccs.uq.edu.au/index.html?page=179372&pid=70702>

10–15

HIV Vaccines

Colorado, United States of America
www.keystonesymposia.org

● **March**

5–7

Vaccine World Summit India 2013

Pune, India
<http://www.researchraven.com/conference/2013/3/5/vaccine-world-summit-india-2013.aspx>

Diary

Key national HIV community, professional and research organisations have come together to create
The Melbourne Declaration 2012
and to take action on HIV.

Australia has committed to reducing rates of HIV infections by 50 per cent, by 2015. But if we are to meet this target, we have to take action now. **The Melbourne Declaration** identifies four action areas that – if effectively implemented – will get us to where we ought to be in the fight against HIV.

The Melbourne Declaration calls on State, Territory and Commonwealth Governments to work with community-based organisations, research centres and professional organisations to:

- 1. Increase uptake of, and better HIV testing**
- 2. Enhance access to antiretroviral treatment**
- 3. Make HIV PrEP available, and**
- 4. Strengthen a partnership response and an enabling environment, including support for HIV research and dissemination of information.**

Show your support. Sign the Declaration at
www.melbournedeclaration.com